NAVIGATING THE CARE SYSTEM
Feasibility and Acceptability of the Use of ICT to Support Older People with Multimorbidity

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To moeke and vake,
whose memories will
continue to inspire me.

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"If you can't fly, then run. If you can't run, then walk. If you can't walk, then crawl. But whatever you do, you have to keep moving forward." (M.L. King)

Abstract

Health and social care systems, primarily designed for people with single diseases rather than those with multimorbidity (two or more long-term conditions [LTCs]), are becoming more complex. With increases in the older population, a rise of multimorbidity and greater fragmentation in the care landscape, little is known about how multimorbidity affects the patient's task to find appropriate care in the right place and at the right time (i.e. care navigation). Difficulties in care navigation have proven to cause delays in access and use of inappropriate services. For older individuals with a number of LTCs, there is an urgent need to support them in appropriately navigating the care system to maximise their health and wellbeing.

Using a mixed method design, this study aims to map the personal care network (PCN) of older people (aged 55 years and over) with multimorbidity. It explores the use of Information and Communication Technologies (ICT) to support this patient group in finding their way through the care system. The research involves three stages, addressing the overall question: "Navigating the care system: what is feasible and acceptable with regard to the use of ICT to support older people with multimorbidity?"

A scoping review brings together the limited literature on care navigation in older people with multimorbidity and identifies gaps in knowledge. The results demonstrate that navigating the care system is perceived to be a daunting task for many patients. Patients have to learn through experience, rather than being able to rely on systems and actors within the care environment. The gaps in knowledge and practice, identified in the scoping review, are the drivers of the second stage of the study. Stage two investigates from a patients' perspective, the structure and composition of the PCN surrounding older people with multimorbidity. People and services (actors) involved in the care for this patient group are explored through

data from self-administered questionnaires (n=62) and semi-structured interviews (n=7). PCNs are visualised through Social Network Analysis (SNA), detailing those actors involved in the network and their relationship. The application of framework analysis enables a definition of roles and responsibilities within the PCN. Stage three of the study outlines the process of creating data-driven personas for the design of digital PCN navigation support for the study population.

This study stands at the intersection of care and ICT. With the expansion of research informing design of ICT for care, this study delivers a number of original contributions to the field. First, the study develops and applies a new conceptual framework: Patient-Centred-Design. Patient-Centred-Design is grounded in and connects three distinguished theories (patient-centred care, patient empowerment and user-centred design). Secondly, the use of innovative methods dictated by this conceptual framework provides valuable additions to the field of SNA by comparing pre and post interview maps of PCNs. Thirdly, this study contributes to health and social care by filling current gaps in care navigation in older people with multimorbidity. Finally, theoretical and practical additions are presented to the field of Human-Computer Interaction through the provision of design requirements.

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List of Abbreviations

A&E	Accident and Emergency
ACG	Adjusted Clinical Groups
AKTIVE	Advancing Knowledge of Telecare for Independence and Vitality in Later life
CANE	Context-Aware Framework for Patient Navigation and Engagement
CCG	Clinical Commissioning Group
COPD	Chronic Obstructive Pulmonary Disease
DoH	Department of Health
EDC	Expanded Diagnosis Clusters
EQ-5D	European Quality of Life – 5 Dimensions
GMC	General Medical Council
GP	General Practitioner
HCC	Health Care in the Community
HCH	Health Care in the Hospital
HCI	Human Computer Interaction
IC	Informal Care
ICT	Information and Communication Technologies
LHIN	Local Health Integration Networks
LTC	Long-term Condition
MDC	Multidisciplinary Care
MMR	Mixed Method Research
NHS	National Health Service
ONS	Office for National Statistics
PCN	Personal Care Network
PICO	Patient, Intervention, Comparison, Outcomes

QOF	Quality and Outcome Framework
RCGP	Royal College of General Practitioners
SCIE	Social Care Institute for Excellence
SNA	Social Network Analysis
SOCC	Social Care in the Community
UCD	User-Centred Design
UK	United Kingdom
USA	United States (of America)
WHO	World Health Organisation

1

Background to the Present Study

This chapter identifies and establishes the academic and applied context in which this doctoral study was conducted. It introduces the core policy requirements and drivers in the care environment that influence the way in which health and social care are constructed in our society. As the primary research was conducted across England, there is an appropriate focus on the structures and policies of this country. At the same time, changes in our society challenge many of the principles and structures underlying health and social care; for example, the increased access to technological applications (Wagner et al., 2010), global demographic changes (World Health Organization, 2014), and expanding knowledge and expertise in medicine (Detsky et al., 2012).

The chapter is organised in two main parts. Firstly, section 1.1 provides a discussion of the changes in society and the concomitant transformations in the care landscape. Secondly, section 1.2 outlines the rationale for this doctoral research, i.e. *"the study of the feasibility and acceptability of Information and Communication Technologies (ICT) to support older people with multimorbidity in their navigation through the care system."*

1.1 A changing society, a transformed care landscape

1.1.1 A changing population

Particular changes in current society are posing several challenges to health and social care. One of the core examples is the increase in life expectancy. On a global

scale (Figure 1) the World Health Organization (WHO) reported an average increase of six years in life expectancy between 1990 and 2012 (WHO, 2014a).

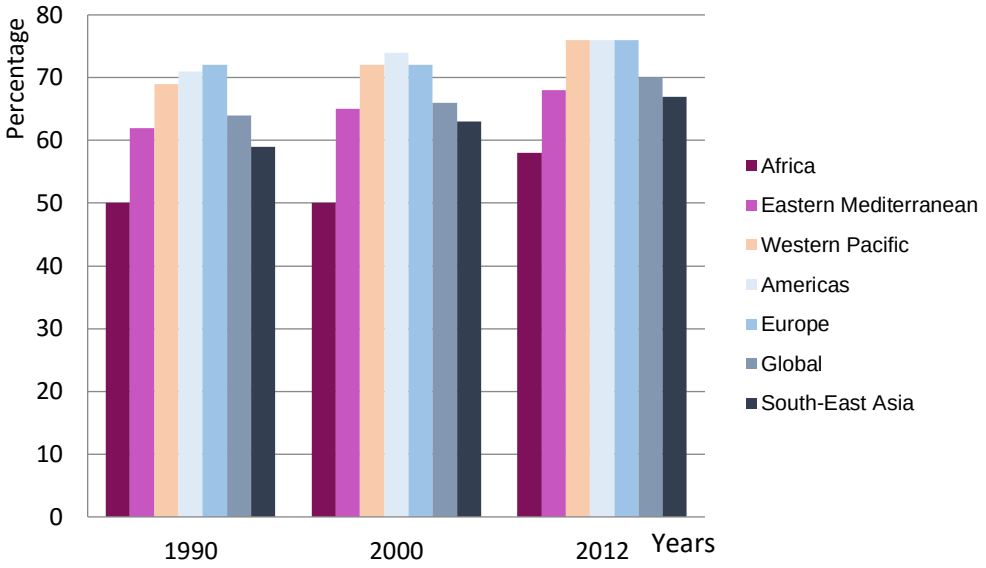


Figure 1: Global life expectancy in years at birth by WHO region (WHO, 2014a)

Whilst a gap in life expectancy between high and low-income countries remains, all are increasingly facing a proportional rise in their ageing population (WHO, 2014a). It is projected that this trend will continue over the next decades with almost 30% of the population in the United Kingdom (UK) expected to be 60 years or older in 2035 (Figure 2).

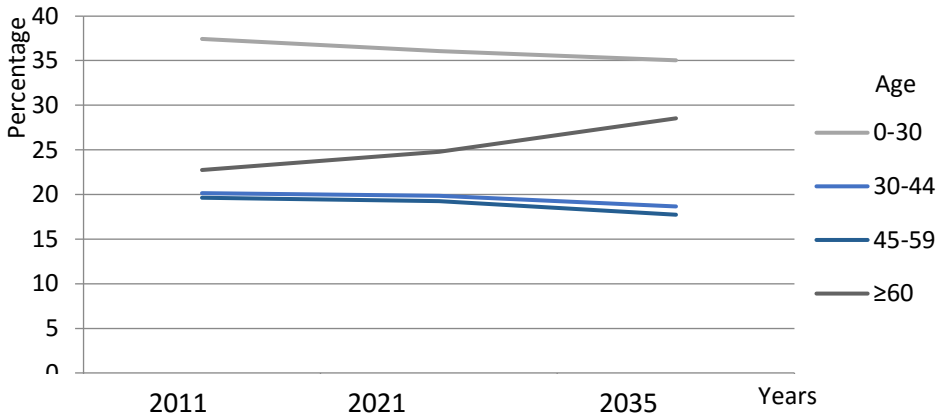


Figure 2: Age groups as percentage of population in the UK for 2011, 2021 and 2035 (Office for National Statistics [ONS], 2011)

An ageing population could be said to reflect progress, for example, related to health care and political stability with the outcome that people are, on average, living longer. However, life expectancy is increasing more rapidly than disability-free life expectancy (ONS, 2014; National Institutes of Health, 2011); whilst people live longer they do not necessarily live well for longer (Jagger, 2015). Along with the increase in life expectancy, there is an increase in long-term health conditions (LTCs) (Department of Health [DoH], 2012; Jagger et al., 2016).

The terms 'LTC' and 'chronic disease' are frequently used interchangeably and definitions in the literature vary. Some sources only include diseases in terms of pathophysiological processes (e.g. heart failure); others broaden their view by also looking at conditions (e.g. risk factors such as hypertension) (Boeckxstaens, 2014). The DoH, defines **LTC**s as:

> *"Those conditions that cannot, at present, be cured, but can be controlled by medication and other therapies" (DoH, 2012a:3).*

Life for a person with a LTC is forever altered; there is no return to 'normal' (DoH, 2012a). This chronic nature of LTCs contributes to the growth in care demands and

number of users; as well as the need for different types of care (Morse, 2014; National Health Service [NHS], 2014). The prevalence of LTCs increases with age, from 9% in the youngest age group (0-4 years old) and reaching 68% in those aged 75 years and over (Figure 3) in 2011 in Great Britain (England, Scotland and Wales) (ONS, 2013). Numbers relating to the reported increase in LTCs over the last decade tend to differ; again, according to which definition is applied and therefore which conditions or diseases are included. Using the definition above, the DoH (2012a) reported that in 2011 around 15 million people in England were diagnosed with a LTC.

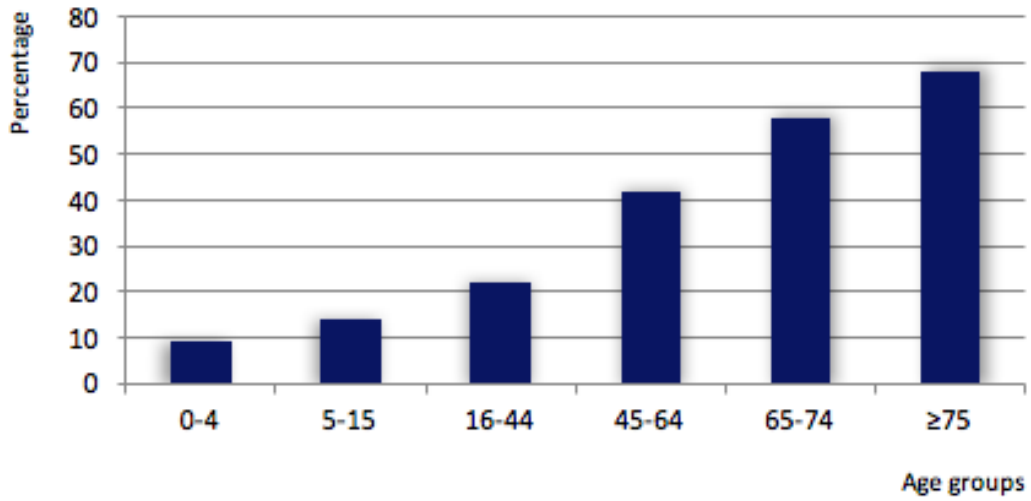


Figure 3: Prevalence of long standing illness or disability in 2011 in the General Lifestyle Survey in England (ONS, 2013)

Whilst the number of people with one LTC is projected to remain relatively stable over the next ten years, it is expected that those living with multiple LTCs will rise from 1.9 million in 2008 to 2.9 million in 2018 (DoH, 2012). If an individual is diagnosed with two or more LTCs, this is referred to as **'multimorbidity'** (DoH, 2012a; Le Reste et al., 2015; Salisbury et al., 2011; WHO, 2008). This initially seems straightforward but, as previously discussed, it depends on what is considered or defined to be a LTC at first. As a result, the estimated prevalence of multimorbidity differs greatly and varies according to definitions: for example, whether or not a

particular list of diseases is used or whether mental health issues, social problems and risk factors are included as well as somatic diseases (Boeckxstaens, 2014; Salisbury et al., 2011). The prevalence of multimorbidity further differs according to population (e.g. older versus younger people, deprived area versus less deprived area) and setting (e.g. the general population versus primary care) (Boeckxstaens, 2014).

Managing LTCs has become an important task of primary care (Goodwin et al., 2010). In 2004 the Quality and Outcome Framework (QOF) was introduced across UK primary care settings. The QOF was part of the general medical services contract in April 2004 and participation by practices was voluntary (Health and Social Care Information Centre [HSCIC], 2005). The framework was intended to support improvement in the delivery of primary medical services and financially rewards general practitioners (GPs) for the provision of high quality care (British Medical Association, 2015). The QOF also rewards practices for managing some of the most common LTCs such as diabetes and asthma (HSCIC, 2015). When initially published, the framework included ten LTCs. Ten years later this number had doubled (Appendix 1). Despite the inclusion and management of the most common LTCs, important other LTCs (e.g. liver disease) are not included in the QOF (British Medical Association, 2015; Coulter et al., 2013; Salisbury et al., 2011).

Alongside the requirements of the QOF, over 1200 general practices and 42 Clinical Commissioning Groups (CCG) in the UK, the latter being statutory NHS bodies responsible for the planning and commissioning of health care services for their local area (NHS England, 2015a), apply the Johns Hopkins Adjusted Clinical Groups (ACG) System (John Hopkins University, 2014). The ACG system incorporates the management of long-term as well as acute conditions (e.g. acute upper respiratory infection). The ACG System captures and describes morbidity of individuals and whole populations (Ibid). It is generally agreed by researchers and clinicians that this system can support the NHS in addressing the challenges

relating to an ageing population in terms of the increasing prevalence of LTCs and multimorbidity (NHS England, 2015b). John Hopkins University (2014) argued the ACG system to be person-centred and able to capture the multidimensional nature of someone's health. The ACG system is elaborate, containing 264 Expanded Diagnosis Clusters (EDCs). EDCs group diagnostic codes by bringing together those codes that describe the same or related conditions (John Hopkins University, 2016). For example, the cluster 'neurologic' contains all neurology related condition codes (e.g. codes for central nervous system infections, head injury, spinal cord injury and dementia).

A study by Salisbury et al. (2011) has demonstrated that using either the QOF or the EDC to estimate the prevalence of LTCs (and thus multimorbidity) gives remarkable differences in results; each system identifying a completely different prevalence of LTCs. In their retrospective cohort study of 99,997 patients across 182 primary care practices in England, 16% of the sample was diagnosed with more than one LTC according to the QOF and almost 60% had been diagnosed with more than one LTC from the EDCs (Salisbury et al., 2011).

The European General Practice Research Network (EGPRN) provided an elaborate definition of multimorbidity that encapsulates the complexity of the concept:

> *"Multimorbidity is defined as any combination of a chronic disease with at least one other disease (acute or chronic) or biopsychosocial factor (associated or not) or somatic risk factor. Any biopsychosocial factor, any risk factor, the social network, the burden of diseases, the health care consumption, and the patient's coping strategies may function as modifiers (of the effects (impact) of multimorbidity). Multimorbidity may modify the health outcomes and lead to an increased disability or a decreased quality of life or frailty" (Le Reste et al., 2013:3-4).*

In this thesis multimorbidity refers to *"the co-existence of two or more LTCs in one individual"* (Donnelly et al., 2013; Tan et al., 2015). This definition was the one most frequently used in the literature and found appropriate for the research (also see Chapter Two). Unless otherwise stated, this encompasses any LTCs including those that are absent from the QOF; but no acute diseases (in contrast to the definition by the EGPRN given above).

Regardless of the definition used, the prevalence of multimorbidity is increasing (DoH, 2012a; ONS, 2013). The magnitude of the reported increase will necessarily differ dependent on the definition applied. According to Fortin et al. (2007:1016) *"patients with multiple conditions are the rule rather than the exception in primary care"*. As with single LTCs, the occurrence of multimorbidity is strongly related to age (Salisbury et al., 2011). Around 93% of patients aged 45-64 years in Canada are diagnosed with a range of LTCs and similar results have been reported across the world (Fortin et al., 2007).

The likelihood of experiencing multimorbidity increases with age, as does the number of co-morbidities (i.e. additional conditions) one is diagnosed with. A study in primary care by Salisbury et al. (2011) showed that 77% of patients aged 75 years or over had at least one LTC and 44% had more than one LTC. The same study reported an average of seven LTCs per consultation in people aged 75 years or over. Multimorbidity is, however, not confined to older age groups (DoH, 2012a). More recently, a significant proportion of middle-aged people (45-65 years old) are reported to be in a similar position, with a higher absolute number of people diagnosed with a range of LTCs than in the older age groups (Barnett et al., 2012; Fortin at al., 2007; NHS England, 2013a). Those aged 50-64 years are also the largest group in England to report that their activities are limited by disability or health problem(s) (Morse, 2014).

The NHS (2014) reports that LTCs account for 70% of the health service budget and around 76% of older people (aged 65 years and over) will require social care and support at some point (Coulter et al., 2013; Gray and Birrell, 2013). Adult social care needs are becoming more complex and extensive with the rise in LTCs and multimorbidity (Local Government Association, 2015; Morse, 2014). Despite the increase in care demand and complexity, in 2013-2014 local government in England saw its spending on social care services for people aged 65 years and over fall by 17% compared to 2009-2010 (Humphries, 2015) and Fernandez et al. (2013) indicated a fall by 39% of the care packages available to older people. In summary, demands on health and social care are increasing, both in volume and complexity, at a time when available resources are scant. These changes are shaping the care landscape.

1.1.2 A transformation in the care landscape

With the changing nature of health related conditions, the care landscape is moving from acute episodes and *curing* by clinicians, towards the management of chronic, often incurable diseases, which require on-going, continuous *care*. The incurable nature of LTCs combined with the burden they can place on people's lives strengthens the importance of a focus on retaining and improving quality of life and meeting patient's needs within an ageing population (Oliver et al., 2014).

Social and health care needs, in particular among older people with multimorbidity, can overlap and are difficult to distinguish and define (e.g. by commissioners) (Morse, 2014). In this thesis, social care refers to both personal and practical support that is given to people regardless of the type of provider; i.e. formal (e.g. nurse), informal (e.g. family member) and third sector (e.g. voluntary organisation) care.

1.1.2.1 Multimorbidity in the health care system

Once diagnosed with a LTC, people find themselves on a continuum of care (Nolte and McKee, 2008). Any additional LTC (or even acute illness) comes on top of the existing LTCs. Multimorbidity further poses its own specific set of issues. Previous research has demonstrated that LTCs and, in particular, multimorbidity can reduce patients' quality of life (Mujica-Mota et al., 2015) and increase mortality and hospitalisation (Perruccio, et al. 2012; Sinnott et al., 2013). It is further recognised that multimorbidity can increase depressive symptoms and anxiety (Marengoni et al., 2011), increase use of service and consultation rates (Sinnot et al., 2013) and result in functional challenges such as limited mobility (Blozik et al., 2013; Perruccio et al., 2012). Within this complexity of multimorbidity, patients with multiple LTCs report and describe ideal processes of care as being patient-centred (see section 1.1.3) and individualised (Boeckxstaens, 2014).

As care needs of people have changed, so have people's preferences about their involvement in their care. Many are looking to be more involved in and informed about their care (Coulter et al., 2013; NHS England, 2014). Patients with multimorbidity particularly value clear communication, accessibility of providers and support from a 'coordinator' who aids the prioritisation of competing demands for and continuity of care (Boeckxstaens, 2014). Coulter et al. (2013) discussed the importance of professionals caring and doing things with people instead of to them. Ideally, care would support patients' unique set of problems, different priorities and multidimensional decision making (Boeckxstaens, 2014; Coulter et al., 2013).

In addition to the (changed) types of needs, there is the challenge of finding a balance between the 'supply and demand' in care (NHS England, 2014). In times of economic crisis and shortage in resources it is argued that we need to make sure we deliver accessible and affordable care for the individual as well as for

society (WHO, 2014b). Cost-effectiveness and continuity of health and social care are essential for the patient experience (Freeman and Hughes, 2010). **Cost-effective care** refers to a situation where the 'quantity of health' gained as a result from an intervention outweighs the costs of that intervention (Guinness and Wiseman, 2011); whilst **continuity of care** has been defined as:

> *"the degree to which a series of discrete health care events is experienced as coherent and connected and consistent with the patient's needs and personal context" (Haggerty et al. 2003, cited in Freeman and Hughes, 2010:5).*

Freeman and Hughes (2010) specified two aspects in continuity of care, namely continuity of relationship and continuity of management. A third element, continuity of information, frequently forms the foundations for management and relationship continuity (Freeman and Hughes, 2010). Continuity of management requires cross boundary continuity with, for example, good record keeping that allows timely information transfer within and between carers (Ibid). Continuity of relationship relates to the longitudinal caring, for example by consulting with the same clinician (Freeman and Hughes, 2010). Continuity of care was identified as fundamental to high-quality care (i.e. clinically effective, safe, personalised, efficient and cost-effective care), particularly for older patients (Ibid).

Whilst valuing continuity of care and striving for its achievement, the health and social care environment increasingly demonstrate characteristics of specialisation and niche formation (Detsky et al., 2012). Individuals are trained and qualified to provide a specific type of care. This results in progressively more specialisms and sub-specialisms (or niches) (Ibid). Over the last 50 years, 140 new specialities and sub-specialties have arisen in medicine in the United States of America (USA) (Detsky et al., 2012). Although the picture in the UK is not as extreme as that in the USA, the General Medical Council (GMC) also reports high numbers of specialties and sub-specialties in the UK (GMC, 2011). On average, 47 specialties

have been recognised according to the GMC (2011). With 61 specialties, the UK comes in third, after Australia and the USA, regarding the amount of specialities per country (Ibid). For the number of sub-specialties, the UK again finishes in the top three, after Romania and the USA, reporting 40 sub-specialties (Detsky et al., 2012). A similar trend of specialised services is prevalent in social care (Blom, 2004), with different services focussing on different issues. Regardless of the debate on the limitations or benefits of specialisation, as Sheldon (2012) points out, the immediate challenge is that the nature of LTCs demands different skills and structures of care (Starfield, 2011b).

These developments require integration, coordination and collaboration across the health- and social care environment as well as between both systems (Hope et al., 2012; Smith et al., 2013; World Health Organisation [WHO], 2008). **Coordination** is

> *"a function that ensured the patient's needs and preferences for health services and information sharing across people, functions and sites are met over time" (Bodenheimer, 2003, cited in Freeman and Hughes, 2010:5).*

Integration, the term often used interchangeably with coordination, tends to have a wider application. **Integration** of care refers to the general concept of bringing services together and coordination (see above) is one of the methods to do this (Shaw et al., 2011). Poor integration within, but also between, health- and social care raises concerns for the appropriate and effective care of (older) people (Morse, 2014).

Care and other services available to support older people in England are extensive (see Figure 4) (Morse, 2014). Unfortunately, this does not necessarily mean that all patients' needs are being met (Ibid). The latter depends on how well the parts within and between the care systems (health and social) work together (Morse, 2014).

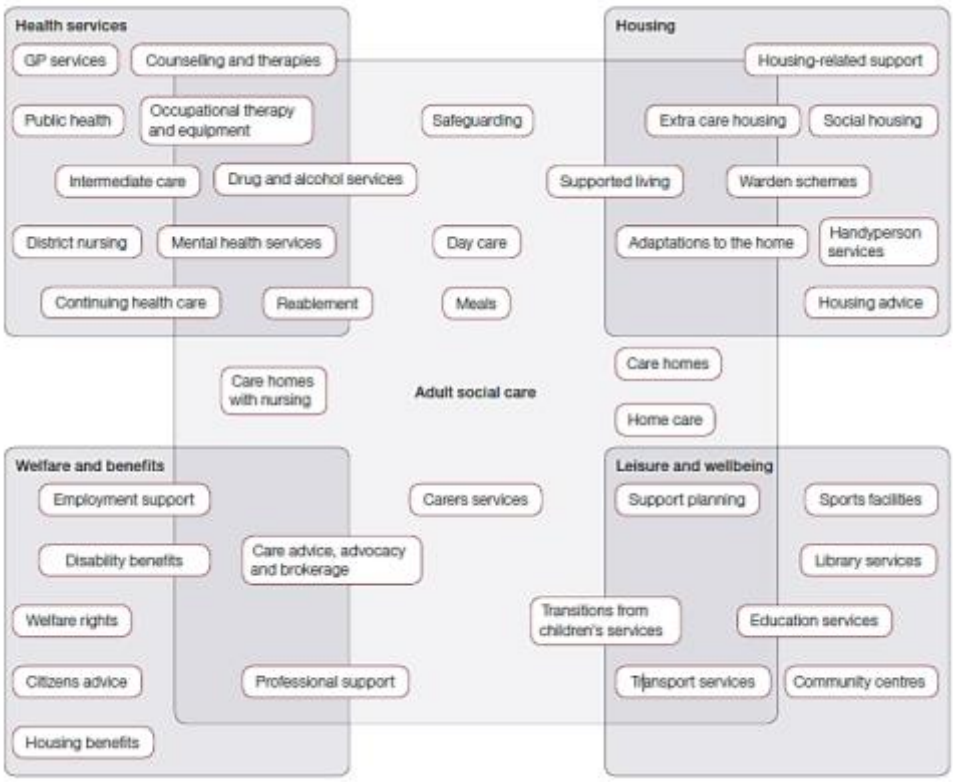


Figure 4: Adult care and other services (Morse, 2014:6)

1.1.2.2 Multimorbidity in the social care system

Since the NHS was formed in 1948, social care has been a distinct entity from health care in England (Gray and Birrell, 2013). Although all health services were free of charge at the point of delivery from 1948, social care services were administered by local authorities in the nineteenth century and charges could be made (Thane, 2009) (also see section 1.1.3). The complex and interrelated needs of older people with multimorbidity, increase the pressure on both systems. Whilst social care needs are rising, available allocated budgets continue to fall (Humphries, 2015; Morse, 2014).

Both formal and informal care (IC) givers are providing social care to older people (Morse, 2014). Publicly funded care only captures a minority of the social care that

is being delivered (Ibid). An estimated 18% of people with LTCs receive state-funded care (Coulter et al., 2013). Many adults pay for some, if not all, of their formal care services (Morse, 2014). Whether or not older people with multimorbidity are eligible to receive government funding (e.g. personal budgets providing people with an amount of money to purchase social care) to address their social care needs depends on the balance, or indeed imbalance, between their needs and means (Baxter and Glendinning, 2014; Morse, 2014). According to Morse (2014) the majority of social care in England is delivered by unpaid family, friends and neighbours (i.e. informal care givers). This group of unpaid caregivers assist with personal care, practical help and coordination of formal services.

Central government sets the national policy on social care in England (Morse, 2014). As such they determine the duties of local authorities and the amount of funding for these authorities (Ibid). Since adult social care separated from children's social care in 2006, several documents and policies have been published that shaped social care in England (Gray and Birrell, 2013). One recent document, the *'Care Act'*, was published in 2014 and brought all laws around adult care and support together into one comprehensive record (DoH, 2014). The Care Act demands that provision across health and social care is better integrated. The document outlines the care and support people are entitled to in England and what support or services should be provided (Ibid). Whilst some of the changes around payment and complaints planned to be implemented in April 2016 have been delayed until 2020, the majority of the Care Act came into effect in April 2015. The Care Act emphasises: the need to support the wider community (e.g. building resilient communities); identify the care and support people need (e.g. social care self-funders can ask for a needs assessment); to deliver person-centred care (also see section 1.1.3) and support across service provision; to ensure adults are safeguarded at all times; and, that services should work together more effectively (Baxter and Glendinning, 2014; DoH, 2014).

1.1.2.3 Multimorbidity across care systems

In order to meet the complex health and social care needs of the ageing population, all parts of and across the system need to work together (Morse, 2014). As much as this can be seen as a challenge, it also provides opportunities. It demands a rethink of care systems and models of care (Coulter et al., 2013; Salisbury et al., 2011), considering how to balance the need for both specialists and generalists in care (Salisbury et al., 2011).

1.1.3 From disease oriented to person-centred care

Changes in society and transformations in the care landscape have resulted in a shift in the way care is conceptualised (Baker, 2014; Humphries and Wenzel, 2015). In their *'Five-Year Forward View'* NHS England (2014) emphasised the importance of adapting to these challenges in society, taking advantage of the opportunities (such as technology and science) when transforming the care landscape (NHS England, 2014).

The way in which the health care system was initially constructed (i.e. curing acute or single events) resulted in the development of measures for (bio) physical imbalances (e.g. blood sugar levels) (Elliott and Dreer, 2007). Not only did this contribute to improved practice and outcomes, it also allowed an indication of patients' progress (Ibid). Some of the needs and demands the care system currently faces (e.g. health related quality of life) are not always 'measureable' in the same way (Green et al., 2002). Health related quality of life, for instance, might not be as straightforward to measure as increases in blood sugar levels. Measuring or even defining elements such as wellbeing and burden of multiple LTCs is much more dependent on the individual's experience (Ibid). In other words, this places an emphasis on individuals as experts with regard to their needs, demands and measures (Coulter et al., 2013). For example, the EQ-5D (European Quality of Life

– Five Dimensions) is an instrument that can provide an insight into the perceived quality of life (Dolan et al., 1995; EuroQol Research Foundation, 2016), but again, multimorbidity provides its own set of difficulties and care needs (Agborsangaya et al., 2013); some of which do not immediately lend themselves to be measured in terms of improvement (e.g. integration of services) (Green et al., 2002).

The disease-based model, which dominated medicine for decades, is no longer sufficient to address the different types and combinations of care needs and demands seen today (Coulter et al., 2013). This model determined the way in which NHS health care was originally constructed. The social care system developed separately from the NHS (Gray and Birrell, 2013) and fell under the responsibility of local authorities. From 1948, these authorities either delivered the services directly or relied on independent institutions that were supervised by them (Thane, 2009). Care was typically provided by faith organisations, voluntary associations and family (Thane, 2009). From the 1950s, but particularly in the 1980s and 1990s, the focus switched from institutional social care to community social care (Thane, 2009). The social care system started to become more structured in 1970 (Gray and Birrell, 2013) and service fees increased (Thane, 2009). Single local social service departments were implemented in each local authority under the '*Local Authority Social Services Act 1970*' (Thane, 2009). These departments became responsible for e.g. meals and recreation services, social support work and domestic help (Ibid).

Although health and social care needs of people often overlap, both parts of the system are still largely separate from one another in England (Gray and Birrell, 2013) and poor integration between the systems continues to be subject of discussion (Thane, 2009). However, on a practice level, multidisciplinary teams have been reported to ensure integration of health and social care in certain Care Trusts in the UK (e.g. Thistlethwaite, 2011).

The type of care and support people need, differs and depends on the individual (Coulter et al., 2013). Since LTCs are incurable, it becomes a matter of meeting patients' needs and assuring the person can have the highest quality of life possible in their unique situation (Green et al., 2002). A care model that focusses on the person and his/her unique situation rather than on the disease, i.e. a person-centred or people-centred care model, is now emphasised (Coulter et al., 2013).

The term 'patient-centred care' has been used to describe an approach to the assessment of individuals and the provision of services over the last four decades (e.g. see Byrne and Long, 1976). It is seen as a critical element of modern health and social care (Leplege et al., 2007). Although the move toward organising care around the patient and his/her needs instead of around diseases (Fortin et al., 2007) only started having an impact on health care practice later in the 1990's and in the 21st century (Royal College of General Practitioners [RCGP], 2014), its origin dates back to social care in the 1950s (Wolfensberger, 1972). Social care was the driver of the concept 'person-centred care' and more recently the health care environment has been using this term to describe their holistic approach (RCGP, 2014). It is often seen as an attempt to move away from the connotation 'patient' might have in the care context (i.e. sick or disabled) (Ibid), encompassing the concept of accumulating knowledge of people, including context information; thus focussing on the 'whole person' (Starfield, 2011a). Although the person-centred versus patient-centred debate is beyond the scope of this thesis, it is recognised that a range of literature is available nuancing and comparing the terms (e.g. Goodrich and Cornwell, 2008; Starfield, 2011a).

To help challenge potential negative associations that come with the term 'patient', to acknowledge that this term is commonly used in the field of health care and understood by both (health and social care) professionals and the public (RCGP, 2014); patient- and person-centred care are used interchangeably in this

thesis. Regardless of the term used, patient/person- centred care in this doctoral study refers to:

> *"Care that is holistic, empowering and that tailors support according to the individual's priorities and needs" (RCGP, 2014:5).*

Which term (person-centred or patient-centred care) is used in this thesis, is greatly determined by the source the information is drawn from. In addition, the patient or person with multimoribidty can also be referred to as a 'user'. This is particularly true for this thesis standing as it does at the intersection of care and technology. As such this term is used interchangeably with person and patient; all of whom are referring to the (older) individual(s) and his/her context (unless stated otherwise).

The Health Foundation defined four key principles to person-centred care as shown in Figure 5. Prior to the person-centred care model being applied across (health) practice, the precept of treating people with **'dignity, respect and compassion'** was already embedded in the NHS Constitution (The Health Foundation, 2014). However, person-centredness of care involves a more complex range of processes. It also requires providers and services to deliver **coordinated** care and support or treatment across multiple episodes and over time. When people transition through services, providers need to be clear as to who is responsible for care coordination (Ibid).

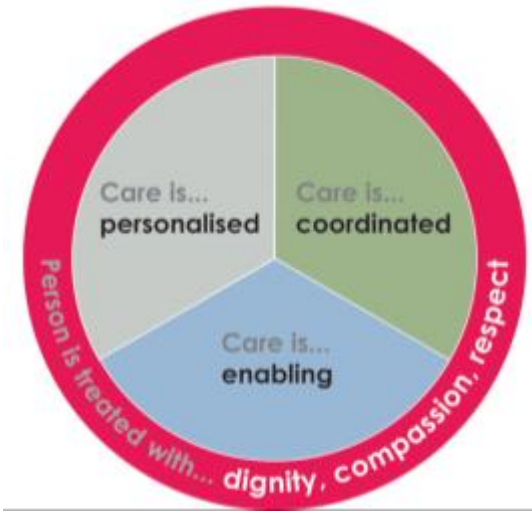


Figure 5: Four principles of person-centred care as published by The Health Foundation (The Health Foundation, 2014:7)

Critically, person-centred care should be care, support or treatment that is **personalised** (also see section 1.1.5.1) (Coulter et al., 2013). As such it is tailored to the needs of each individual rather than to their diagnosis or condition (Ibid; The Health Foundation, 2015). Those things important to the patient and his/her family, are emerged at the assessment process to act as a foundation for any subsequent treatment and care. The fourth and final principle of person-centred care according to The Health Foundation (2015), is that it needs to **enable** patients to recognise and build on their strengths for recovery. Working from a positive approach instead of a deficit view further allows for patients to perceive themselves and be seen as assets instead of 'burdens' (Coulter et al., 2013; The Health Foundation, 2015). Providers are to help patients recognise, engage and develop their own resources to live life as well as they can (The Health Foundation, 2015).

1.1.3.1 Empowerment in person-centred care

In the patient-centred care model, often in contrast to the disease-based model, it is no longer sufficient to have the physician state what the patient should or

should not do or how treatment will proceed (Coulter et al., 2013). The individual patient's narrative becomes equally important (Coulter et al., 2013). This drive towards patient-centred care does not negate the support some people may need to self-manage their condition(s), carry out self-care (Coulter et al., 2013) or even their journey to become actively involved in their care plan (Greene and Hibbard, 2012; Hibbard and Gilburt, 2014). In other words, they need to be empowered. In England, both the DoH and the NHS have highlighted patient empowerment (also see section 2.4.1.2) as an additional concept that could help shape the patient-centred care model. Patient-centred care and patient empowerment in health care is about enabling people to manage their conditions (Coulter et al., 2013; Smith et al., 2013); acknowledging their responsibility as well as the importance of their input in their own care plan (Coulter et al., 2013; Greene and Hibbard, 2012; Smith et al., 2013). In social care, and increasingly in health care, empowerment results from participation in the development of services as well as the use of services (Beresford, 2007; Davies et al., 2013). This ideology is similar to that of empowerment through co-producing products via user-centred design (UCD) (also see section 2.4.1 and 2.4.2).

As illustrated in the *'Delivering better services for people with long-term conditions: Building the house of care'* report (Coulter et al., 2013), patients are to become the driver of the care planning process. This may indeed, for example, include the provision of support to enhance patient's ability to self-manage (Coulter et al., 2013). Putting the patients' own expertise in the mix and placing them at the heart of the delivery system requires patients to participate in their care plan; to indicate their needs and goals (Coulter et al., 2013; NHS England, 2013b; WHO, 2008). Their perception of their quality of life becomes essential. Patient-centred care goes hand in hand with goal-oriented care as they take up this active role. As such, patients are encouraged to become more knowledgeable and actively involved (Coulter et al., 2013). Active participation during

consultations, for example, by asking questions to the GP (Haywood et al., 2008; Tran et al., 2004) or being engaged in their own health plan has been shown to increase patients' satisfaction, wellbeing, health status and continuity of care (Coulter et al., 2013; Dimoska et al., 2008; Kinnersley et al., 2008). Patient activation has also proven to be beneficial in terms of preventative care, demonstrating that more 'activated' patients are more likely to receive preventative care (Greene and Hibbard, 2012; Hibbard and Gilburt, 2014).

1.1.3.2 Information exchange in person-centred care

This partnership model of care, where both the patient and the care provider strengthen each other and share responsibility, demands good communication between those involved (Cegala and Post, 2009; Coulter et al., 2013; Schwartz et al., 2010). For continuity and quality of care (also see section 1.1.2.1) the exchange of information (disease but also context specific) is invaluable. This applies to exchanges between patients and clinicians, as well as between all caregivers including social care and health professionals (beyond primary care) in the multidisciplinary team that surrounds the patient (Coulter et al., 2013; DoH, 2012a; Weiner et al., 2005). Such interactions are crucial when it concerns patients with multiple morbidities as they not only move within, but also between services and settings (The Health Foundation, 2015).

1.1.4 Ageing in a digital age

Not only has our society faced different population dynamics (e.g. an ageing population) in recent decades, the environment in which we age has similarly radically changed. Technology is influencing and affecting our daily life. Computers were originally used by trained 'experts' to carry out science, engineering and business-focused tasks (Campbell-Kelly et al., 2013). One had to possess programming skills and it was impenetrable to those who did not have these or

did not need to use such computers (Wright and McCarthy, 2010). In recent years, such exclusivity has broken-down with the presence of technology further increased through our daily interactions with smart devices (e.g. tablets, and smartphones) (Preece et al., 2015).

In November 2012, the UK government published the *'Government Digital Strategy'* (Cabinet Office, 2012). This report outlined the changes and approaches the government was to take in making its services 'digital by default' following the idea that *"central government where possible must become a digital organisation"* (Cabinet Office, 2012:5). **Digital by default** refers to

> *"Digital services that are so straightforward and convenient that all those who can use them will choose to do so while those who can't are not excluded" (Cabinet Office, 2013:11).*

However, there would seem to be a gap between this policy rhetoric and the reality for many individuals (or organisation). Around 35 years ago digital access began to move out of high-tech environments and people started to use computers at home (Wandke et al., 2012). Even though computers have become ubiquitous, there is still a gap between younger and older people accessing computers. In its report *'Digital Britain 2'*, the Cabinet Office (2013) reported that overall 83% of the British population is online. Those who go online feel relatively comfortable in doing so with around 90% feeling confident in using the internet (Cabinet Office, 2013).

A difference according to age is visible regarding the number of people being online. Just over 90% of younger people (15-64 years old) and 51% of older (aged 65 years and over) people are online. A similar, but smaller, gap in Britain is seen according to socio-economic class. Just over 90% of people in the higher socio-economic class are online compared to 74% of people in the lower socio-economic class (Cabinet Office, 2013). It is this digital divide (i.e. differences in accessibility

of technology) that is often the subject of discussion when talking about digitalisation (Green and Rossall, 2013). The same can be said about usability of technology amongst certain populations (e.g. older people) (also see Chapter Five).

1.1.4.1 Use of technology for personal reasons

Older people are the fastest growing consumer group of internet users and are keen users (Wagner et al., 2010). For the first time, society has reached a point where the number of older people (aged 65 years and over) who have used the internet has overtaken the number of people who have never used it (Green and Rossall, 2013). When including those who are 55-64 years old (and thus the age group of 55 years and over), the picture has changed even more; twice as many people have used the internet compared to those who have not (Ibid). Older people are using the internet for the same purposes as younger adults do, but carry out different activities to a different extent (e.g. more emphasis on e-mailing than on online gaming) (Green and Rossall, 2013; Wagner et al., 2010). Communication and social support are the two most common reasons for using the internet (Ibid). Older people are reported to use different types of online communication including instant messaging and online fora (Wagner et al., 2010). Immediate benefits of this online environment are perceived as increased contact with family (especially grandchildren) and friends, bridging the geographical boundaries or limited mobility and coping with grief (Wagner et al., 2010). Technology is used for both personal and health goals in older people (Wright and McCarthy, 2010).

1.1.4.2 Use of technology for care purposes

Alongside the personal use of digital devices, the improvements Information Communication Technology (ICT) could bring in health and social care (in particular to the quality of, especially, later life) is acknowledged. The evidence

regarding the use of ICT in care, and especially in later life, is ambiguous. Some studies show an increasing amount of older people using ICT (Wagner et al., 2010; Wandke et al., 2012); others are more reserved (Czaja, 2015). Some commentators perceive older people as a 'lost cause' with regard to technology, whilst others note a high awareness of the benefits and importance of ICT, even amongst those who see themselves as 'digitally dismissive' (Age Concern and Help the Aged, 2010). ICT can support social networks, transform services to help people live independently at home for longer, empower people and increase their participation (Age Concern and Help the Aged, 2010). However, the benefits of ICT depend largely on how well it is designed.

1.1.4.3 Older people and technology design

Although technology use seems to decline with greater age, this is less so when the technology use is more established and easier to use (Eisma et al., 2004). Since ICT is no longer restricted to 'expert use' only (Wright and McCarthy, 2010), one cannot always assume a certain set of skills or knowledge will be present in the user. Regardless of the exact numbers and their variations, it is likely that the use of ICT in daily life, including that of older people, will further increase as it becomes more embedded in our society (Green and Rossall, 2013). It is also expected that technology (e.g. web access devices) will soon be more affordable for older people (Green and Rossall, 2013), which might further increase its accessibility and use. The potential benefits of ICT in care (Age Concern and Help the Aged, 2010) add to the importance of exploring this field. Moreover, the current group of middle aged people are the older-old of tomorrow. This makes digital inclusion, research and design processes in this area a priority. Although many younger and middle aged people are familiar with the use of today's computers and digital devices, the progressive nature of technological developments makes it unlikely that they remain comfortable with future applications (Wandke et al., 2012). We need to find ways to involve middle aged and older people in the design of ICT systems.

Without successful ways to do this, the current issues regarding 'older people' and 'technology' are likely to repeat themselves in the future.

1.1.5 Person-centred care in a digital age

1.1.5.1 The concept of personalisation in care and technology

As previously discussed (section 1.1.3), the overall intention of person-centred care is to deliver care as a partnership between the patient (his/her relatives) and his/her carers and professionals, tailored to the needs and goals of that specific individual (The Health Foundation, 2014), i.e. in this thesis the older person with multiple morbidities. Person-centred care attaches great importance to empowering individuals, enabling them to be actively involved and provide personalised care. Personalisation in care is a broad and complex domain in itself. The specifics and details surrounding this concept are beyond the scope of this thesis. However, overarching lines can be drawn between personalisation in care and in Human-Computer Interaction (HCI). The DoH described **personalisation in care** as:

> *"Every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings" (Dunning, 2008).*

Personalisation in care, requires people to think about their care and support needs and how they would want to meet those (NHS, 2015). In this thesis the term 'personalisation' acknowledges the fact that it means different things to different people (Social Care Institute for Excellence [SCIE], 2009a), it refers to the idea of *"making sure the right help gets to the right people"* (SCIE, 2009b:2) and implies that we *"find new ways to give people more choices"* (SCIE, 2009b:1) so that care is self-determined and self-directed (SCIE, 2009a). As such, it goes beyond the use of, for example, personal budgets in social care (SCIE, 2009a).

Personalisation has not only gained popularity in health and social care. About two decades ago, the field of technology began to emphasise this concept (Meena and Sivakumar, 2015). One of the most straightforward definitions of **personalisation** in the context of **technology** was given by Blom (2000):

> *"Personalisation is a process that changes the functionality, interface, information content, or distinctiveness of a system to increase its personal relevance to the individual" (Blom, 2000, cited in Blom and Monk, 2003:195).*

In the field of technology, two different trends in terms of personalisation are relevant to the context of this thesis. Firstly, research in the field of HCI has been focussing specifically on understanding how to best design systems to support users' goals, needs and values (Meena and Sivakumar, 2015). Personalisation in HCI and technology has the potential to optimise services for the individual user (Lee, 2013). Depending on the piece of technology, personalisation can be undertaken by the system or the user. It can be targeted at the individual level or for categories of users and different aspects (content, functionality, user interface, and information access) can be adjusted (Ibid). Doing this is believed to improve outcomes of technology use in terms of satisfaction, loyalty, motivation, efficiency, attention, memory and motivation (Lee, 2013). Secondly, technical and commercial developments in eHealth (health care practice supported by ICT) and mHealth (health care practice supported specifically by mobile technology) have been introduced with the intention of improving the quality of care (Ali et al., 2016; WHO and International Telecommunication Union, 2012:1).

An increasing amount of literature is dedicated to the use of ICT in care settings to, e.g. deliver tailor-made programs and interventions (Yardley et al., 2015). In the last decade, there is an acceleration of research in health care regarding the use of electronic applications (e.g. Clark and Goodwin, 2010; Sanchez et al., 2013; Stroetmann et al., 2011). A rapidly growing interest for e- and mHealth to improve

aspects of care, including social care, or to support person-centre care is noted (Gee et al., 2015; WHO, 2011). The internet is gaining popularity among people of all ages, for all kinds of purposes e.g. to communicate with their social network or to share aspects of their personal lives, as well as to gain information or become informed about their health (Green and Rossall, 2013; Wagner et al., 2010).

1.1.5.2 Adoption and practice of ICT

So far, the adoption or uptake of ICT in daily practice of health and social care seems low, both among professionals and patients (Wachter, 2016; Ward, 2013). Thus, although digitalisation started to enter health and social care, its full potential and adaptation has not been reached. Beeuwkes-Buntin et al. (2011) pointed out that implementation strategies for health IT could be improved. Ideally, improving implementation needs to start before the actual implementation takes place. This would ensure that unintended consequences of technology adoption can be identified throughout the process of product development (Beeuwkes Buntin et al., 2011). The design of programs and ICT interventions in health and social care are found to directly influence their chances for effective adoption (Kim and Park, 2012; Ward, 2013). The use of electronic medical health records for instance became the standard (Häyrinen et al., 2008; Wachter, 2016) to register and share information and improve the overall communication in health care (DoH, 2012b; Gulmans et al., 2007; Robertson et al., 2010). Personal health records on the other hand (held by patients and shared with their provider) did not have this successful uptake, even though they were perceived as similarly effective in supporting information sharing and overall communication (Logue and Effken, 2013; Pagliari, 2007).

Studies on eHealth often yield mixed results. Reports showed measurable benefits resulting from the adoption of information technology by users (Beeuwkes Buntin et al., 2011). The initial findings of the *'Whole System Demonstrator Programme'*

for example, reported a 20% decrease in emergency admissions, a 15% reduction in Accident and Emergency (A&E) visits, a 14% reduction in bed days and 45% decrease in mortality rates (DoH, 2011). However, two years later, Henderson et al. (2013) concluded, for that same study, that telehealth was not cost-effective in addition to standard support and treatment.

Regardless of the mixed results in cost-effectiveness (Henderson et al., 2013), the use of ICT to improve several aspects of care is found to be promising, especially when well-designed, and worth exploring (European Commission, 2014). Governmental bodies have started to include the topic of ICT in care in a range of policy documents. Within this context the *'Digital agenda for Europe 2010-2020'* was put in place (European Commission, 2014). The DoH in England aligned with this plan in its *'Digital Information Strategy'*, published in May 2012 (DoH, 2013). The information strategy displays a ten-year framework for the transformation of information in the NHS. With the goal of having a paperless NHS by 2018, key commitments in this publication include online appointment booking and ability for patients to view their general GP's record online by 2015 (DoH, 2013). Another report was published by Liddell et al. (2008) focussing on the use of technology for patient care in the NHS and Wachter (2016) discussing how to make IT work to improve care in England.

1.1.5.3 Designing ICT tools for the care setting

Whether technology is used to aid independent living among older people, assist them in their daily lives, maintain their health, manage their conditions and improve their quality of life or to inform them, it needs to be designed with the end-user in mind (Peeters et al., 2012; Wachter, 2016). In other words, the systems and devices should suit older people's needs, mitigate challenges (e.g. cognitive or communication difficulties) and provide them with benefits (Khosravi and Ghapanchi, 2016).

Previous initiatives regarding ICT in care settings (e.g. electronic health records) as well as in other disciplines, demonstrated that the process through which ICT systems are designed influences the likelihood of acceptance and adoption by the intended end-user (Kim et al., 2014; Kim and Park, 2012; Peek et al., 2014). This means that, when designing innovative systems, depending on the end-user, different attributes of the system might be important. For example, to clinicians, the perceived *usefulness* is more likely to influence their chance of accepting the system than the *ease of use* (Ward, 2013). The adoption of systems (by older people) depends on how well it fits with the end-user's values, their experiences and needs; the degree to which the system can be tried out before it is fully implemented; the extent to which the (positive) results of the system are visible to the individual; the ease of use and the degree to which the system is perceived as a 'better' alternative (Peeters et al., 2012). In their study Peeters et al. (2012) concluded that there is particular room for improvement in terms of communicating the way in which the innovation will be beneficial to the end-user and the visibility of its (positive) results. This links back to the discussion on personalisation (section 1.1.5.1) and further detail is included in Chapter Five.

To be able to address these elements (e.g. end-users needs), the design team first needs to be aware of the different requirements. As such, there has to be robust and valid research encompassing older people's experience, perceptions and needs around ICT prior to developing, testing and implementing suitable systems and devices.

1.2 Rationale for this study

1.2.1 Person-centred care for patients with multimorbidity

Within the context of our ageing society and the rise of multimorbidity, most of the studies and developed ICT interventions either focus on a specific disability, health problem (e.g. Chronic Obstructive Pulmonary Disease [COPD]) or a specific set of diseases (e.g. COPD in combination with chronic kidney disease) in the case of multimorbidity. Another way of approaching multimorbidity and exploring ways in which care for this patient group can be improved, is by exploring how multiple LTCs affect people regardless of the type and amount of LTCs. This approach aligns with person-centred care as it looks at common consequences for the person involved rather than the diseases per se. As outlined in this chapter, the challenges multimorbidity brings along are unique and different (Agborsangaya et al., 2013) compared to those experienced when diagnosed with a single LTC. Despite the different combinations of diseases patients are diagnosed with (which would be the main focus in a disease based model), one might experience general or common consequences of multimorbidity. Attention has been given to these consequences for patients (albeit often related to a specific set of diseases) as well as for clinicians and the society. For example, people with multimorbidity are at risk of premature death (Vogeli et al., 2007); clinicians might experience difficulties in prioritising consequences that need their attention (Junius-Walker et al., 2012) and our society faces an increase in health care costs (Vogeli et al., 2007).

When exploring the literature, those frequently cited consequences of multimorbidity for patients can roughly be classified into four broad categories: physical and psychological burden of diseases (1), physical and psychological burden of treatment (2), costs or utilisation of services (3) and organisational

issues (4). Examples for each category can be found in Figure 6 and each has various important subcategories as detailed in the same figure.

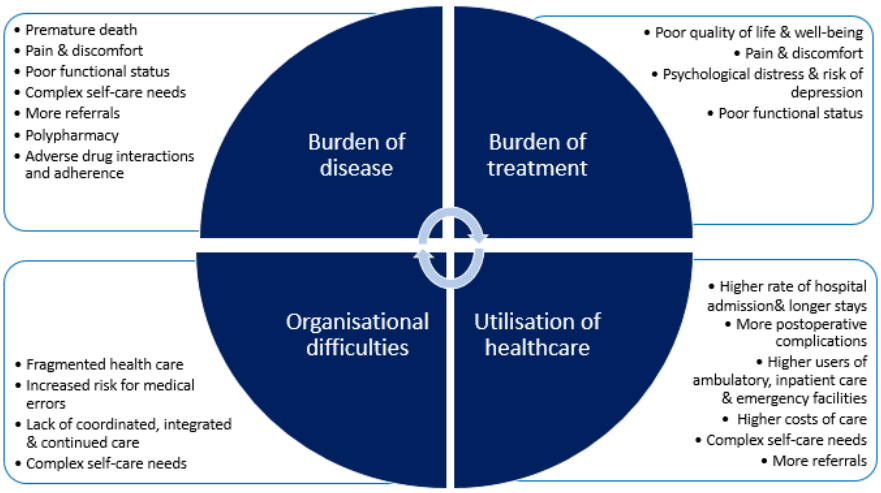


Figure 6: Common consequences in relation to multimorbidity

In the context of patients with multimorbidity, overarching consequences that frequently arise in the literature concerning operational difficulties are issues relating to fragmentation of the care system. Disintegrated and poorly integrated health and social care can result in, for example, poor continuity of care. This issue fosters many discussions at governmental and policy level as it is in direct opposition to the principles of person-centred care (DoH, 2012a; The Health Foundation, 2015; Smith et al., 2013); perceived as the way forward in handling the (upcoming) challenges society faces in relation to its ageing population. Patients with multimorbidity need to consult multiple providers to ensure their conditions are appropriately monitored, managed and (where necessary) treated (Parry and Coleman, 2010; Toscan et al., 2012). However, little is known about the 'practical level' of this phenomenon. Aside from the desire to deliver holistic care (Smith et al., 2013) and to develop models for chronic care (Solberg et al., 2006), we need insight into this 'practical level' of finding the right type of care, at the right time, in the right place for the right problem. In other words, we need to understand such practical level of adequate and sufficient care navigation and

patient's experiences of this navigation process. Not only would this add to the existing body of knowledge, it also allows a picture of the current situation and thus provides a start point to work towards the ideal of integrated holistic person-centred care.

1.2.2 Finding the best route to services: care navigation

As specialisation in health and social care grows (see section 1.1.2.1), research into the practice of care coordination and integration is increasing. Integrated and well-coordinated services would facilitate the task of finding the 'right' care, at the 'right' time in the 'right' place (Rein, 2007). In social care, the term 'case management' has become important in this context (Ross et al., 2011). In health care, the use of 'care navigators' is being explored (Albert, 2012).

In essence, case managers and care navigators both function as bridges between the patient and the various services that are available. They integrate services around the needs of the individual. Case management refers to a 'package' of care organised around the person with LTCs (Ross et al., 2011). The specific term 'care navigator' has its roots in the cancer care setting (Willis et al., 2016). Within this thesis, this is the term chosen to refer to the support given to patients to navigate the care system. Unless stated otherwise, this includes, for example, case managers.

The first care navigation programme was developed by Freeman in 1990 (Huber et al., 2014) and since then studies in the cancer care setting have shown the benefits of care navigators (Huber et al., 2014; Natale-Pereira et al., 2011; Willis et al., 2016). Care navigators are typically concerned with the development of a 'pathway' or 'journey' that guides patients through the early stages after their diagnosis (e.g. who do they need to go to, setting up the appointment). They help patients navigate through the care system. This function, in the cancer setting, is

likely to be held by a nurse (Case, 2011; Pieters, 2011; Seek and Hogle, 2007). Exploring this role from a clinical perspective, there would seem to be evidence as to why this profession is the most suitable to fulfil this role in cancer care (Albert, 2012; Seek and Hogle, 2007).

Today, little is known on how the concept of 'care navigators' fit in the wider health and social care setting, nor in the context of multimorbidity. It remains unclear whether care navigators would be equally beneficial in a primary care setting; whether the concept is transferable; or if there is a need for nuances in this 'new' context. For instance, the involvement of a care navigator in the cancer setting is typically limited in time (the early stages after diagnosis) and fades later in the care process (Seek and Hogle, 2007). It is unknown if this timeframe needs to be expanded in the setting of multimorbidity or if the interpretation of a care navigator can be supported if not broadened to, e.g., ICT. ICT, for example telecare, has been found to provide valuable opportunities for older people, particularly in supporting age-related needs (Goodman-Deane et al., 2008). A number of technological applications are emerging in the field of health and social care as innovative and efficient ways to support older people in their daily life and reduce the cost of health care (Khosravi and Ghapanchi, 2016). However, it remains unknown if and how ICT could support navigation through the health and social care system.

The changes in population dynamics, the increase in LTCs and the rise in multimorbidity are contributing to the need to enable people to live healthy and productive lives for as long as possible (Czaja, 2015). With a focus on patient-centred care, the care landscape demonstrates a partnership model between the patient and provider (Coulter et al., 2013; The Health Foundation, 2014). As mentioned throughout this chapter, this model of care requires patients to play a central and active role in the planning of their care. Managing one's health has become a shared responsibility, requiring patients to be well informed and

empowered (Czaja, 2015). Both of these elements are found to be established and strengthened through ICT (Czaja, 2015), but again, only if the technology used is suitable and accessible for the patient. This growing emphasis on patient engagement further strengthens the case for research in HCI and older people (Marchibroda, 2015).

1.2.3 Filling the gaps in knowledge

Changes in society (e.g. ageing population and digitalisation) and concomitant challenges in the care landscape (e.g. increased demands and changed needs) require us to rethink the delivery of health and social care (Rechel et al., 2009; The International Longevity Centre, 2012). The following two gaps were identified in health and social care literature and formed the foundation for this study.

Firstly, health and social care systems were initially not designed to support the growing number of people living with multimorbidity (Ravenscroft, 2010). A focus on coordination and continuity of care emerged together with a drive towards increasingly specialised services. To address this, single disease settings benefitted from the use of care navigators who brought services together around the patient (Albert, 2012). However, an increasing number of people suffer from more than one (long-term) condition, where the 'pathway model(s)' may be mutually exclusive; whilst delivering 'best-practice' care on one condition may well result in sub-optimal care for the other complex LTCs (Boeckxstaens, 2014). Although the patient-centred care model demands care to be organised around the patient, in practice patients often have to move within, between and beyond different parts of the care system to meet their complex needs. Little is known about how older people with multimorbidity currently accomplish this; how they find the 'right' care at the 'right' time in the 'right' place for the 'right' problem (care navigation); how the appropriate providers and services are selected in relation to patients'

LTCs; or if care navigators would be able to form a bridge in the same way as in single disease settings.

Secondly, the patient or person-centred care model is believed to capture the nature of current care problems better than the disease-centred model, and studies are exploring technological applications to support this model of care (Czaja, 2015; Marchibroda, 2015). The increasing number of older people has a significant impact on health and social care systems globally (Khosravi and Ghapanchi, 2016). A rise in care costs and needs is occurring simultaneously with a growing shortage of clinicians and caregivers (Marchibroda, 2015). The majority of care for patients with multimorbidity is provided in general practice. The current pressure general practice is facing is likely to continue as the ageing population grows (Baird et al., 2016; Clay and Stern, 2015). Research has shown that ICT can provide valuable opportunities for older people, for example by supporting age-related needs (Goodman et al., 2009), whilst also reducing the cost of care (Khosravi and Ghapanchi, 2016).

In this context, ICT holds promise to help our society, and in particular its older members, face these challenges. Research has widely discussed the potential of ICT to enhance independence and improve quality of life of adults as they age (Czaja, 2015). An overview of these benefits can be found in Appendix 2. However, the results of technology to support care in older people are ambiguous. Whether ICT can support this partnership model of care (i.e. patient-centred care) in a meaningful, efficient and cost-effective way depends on several factors, including how well those electronic support tools are designed (Damant and Knapp, 2015). Currently there are no insights into the design needs for, nor the benefits of, ICT on navigation through the care system.

1.2.3.1 Aims and objectives of the study

To address these current gaps, this doctoral thesis aims to explore the feasibility, acceptability, and those requirements that could identify the design of ICT interventions to support older adults with multimorbidity to independently navigate the care system. Three overarching objectives were identified to:

1 Synthesise the literature on care navigation among older people with multimorbidity from a patient perspective (see Chapter Three).

2 Analyse and visualise the structures of and interactions in the personal care network (PCN) of older people with multimorbidity and gain an understanding of their experiences of navigating their PCNs (see Chapter Four).

3 Identify elements for improvement in care navigation among older people with multimorbidity and deliver design requirements for the development of an ICT tool to support this population in their navigation through the care network (see Chapter Five).

The breadth of these objectives was recognised and Chapter Two specifies the methodological considerations that were made in relation to each objective. To structure this doctoral research further, each objective was linked to further corresponding research questions that could help address each objective (see Table 1). Section 2.4.3 details the methods used to answer the research questions linked the objectives stated above.

Table 1: Aims and objectives of the study

AIMS AND OBJECTIVES	RESEARCH QUESTIONS	FINDINGS
Synthesise the literature on care navigation among older people with multimorbidity from a patient perspective**.**	What does the literature regarding care network/system navigation in the setting of older people with multiple morbidities tell us?	Chapter Three
Analyse and visualise the structures of and interactions in the personal care network (PCN) of older people with multimorbidity and gain an understanding of their experiences of navigating their PCNs**.**	What does the care network of older people with multimorbidity look like from a patients' perspective? a) Which actors are involved in the PCN of older people with multimorbidity and from which care domain (social care in the community, health care in the community, health care in the hospital and informal care)? b) Does this structure of the PCN differ according to the number of LTCs, age and sex? c) Why are these actors present in the PCN of older people with multimorbidity?	Chapter Four

AIMS AND OBJECTIVES	RESEARCH QUESTIONS	FINDINGS
	d) Does this reason for involvement differ according to the number of LTCs, age and sex? e) How are actors involved in the PCN of older people with multimorbidity?	
Identify elements for improvement in care navigation among older people with multimorbidity and deliver design requirements for the development of an ICT tool to support this population in their navigation through the care network.	How does the care network of older people with multimorbidity function in the opinion of the patients? How can ICT support patients in the tasks of navigating and interacting in their care network?	Chapter Five

1.2.3.2 Outline of the thesis

Chapter Two discusses the research methodology and study design of the mixed method study carried out in this doctoral study. Chapter Three, brings together the existing literature around care navigation in older people with multimorbidity and thus reports on the first objective set for the study (also see Table 1).

For the second objective, Chapter Four addresses the current gaps in knowledge in relation to the composition of care networks of older people with multimorbidity. It focusses on the selection and involvement of different care providers which are then analysed to form the PCN of that person. The main aim of this chapter was to initially visualise the PCNs of older people with multimorbidity through quantitative data. In addition, the necessary understanding of the functioning of these PCNs was gained through qualitative data.

Chapter Five reflects on the design requirements for ICT, exploring a sustainable system that can support care navigation in older people with multimorbidity (the end-users). This includes the identification of end-users' needs and those elements patients found that could be improved. These data provided the basis for the development of evidence-based personas of older people with multimorbidity. Personas are a method to present characteristics, behaviour, needs, etc., of the end-user and communicate design requirements. As such, chapter five relates to the third objective of this study.

In conclusion, Chapter Six discusses the study findings in comparison to the existing literature, the strengths and limitations of the research, its contributions to health and social care as well as HCI and the provision of suggestions for practice and future research.

2

Methodology and Study Design

This chapter gives an overview of the mixed method research (MMR) carried out in this PhD. As the words 'methods', 'methodologies' and 'paradigms' are used throughout the chapter, the reader is first provided with clarifications of these terms. The second part of this chapter briefly presents the three research paradigms currently standing in social science i.e. positivism (section 2.2.2), constructivism (section 2.2.3) and pragmatism (section 2.2.4). Pragmatism is discussed in more detail as it underpinned the research conducted. In addition, this chapter summarises some of the methodological considerations in relation to research in care technology (section 2.5) and highlights the issues involved when conducting Human-Computer Interaction (HCI) studies within the context of older people (section 2.3). Finally, this chapter gives an overview of the study design (section 2.4), outlines the processes involved in the construction of the instruments for data collection (questionnaire and semi-structured interviews) and the sampling strategies (section 2.6).

2.1 Frequently used terminology and their definitions

From general and more theoretical (at the bottom of the pyramid) towards concrete and more practical (at the top of the pyramid), 'methods', 'methodology' and 'paradigm' relate to each other as shown in Figure 7.

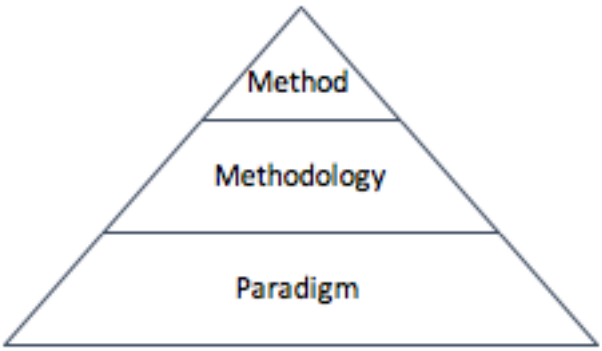


Figure 7: Relationship between paradigm, methodology and method

A paradigm (also see section 2.2) functions as an underpinning theory or a way in which one thinks about the world in which the research is taking place. It is a general perspective on the complexities of the real world; a way of looking at a phenomenon (Polit and Beck, 2010). As such, it influences all 'levels' in the research project that come after. A **paradigm** is defined as:

> *"A worldview, complete with the assumptions that are associated with that view" (Mertens, 2003, cited in Teddlie and Tashakkori, 2009:4).*

These assumptions will guide one's approach to inquiry (Polit and Beck, 2010). Based on definitions of **methodology** given by Clert et al. (2001) and Greene (2006), Teddlie and Tashakkori (2009) came up with the following:

> *"A research methodology is a broad approach to scientific inquiry specifying how research questions should be asked and answered. This includes worldview considerations, general preferences for designs, sampling logic, data collection and analytical strategies, guidelines for making inferences, and the criteria for assessing and improving quality" (Teddlie and Tashakkori, 2009:21).*

The methodology can be seen as a systematic way of addressing a problem, explaining the procedures and the process by which researchers will answer their questions (Polit and Beck, 2010). The three main methodological movements,

deriving from different paradigms, within social and behavioural science are: quantitative oriented research, qualitative oriented research and mixed methods research (Teddlie and Tashakkori, 2009). In addition to the research orientation, the methodology frequently encompasses (and often requires) theories or conceptual models that further guide the methodology and method. These can be seen as extra lenses for the research undertaken and help shape the procedures of the research (Polit and Beck, 2010). In this doctoral study the three additional theories that were selected are described in section 2.4.1.

Methods are the more concrete elements in the research design encompassing steps, procedures and strategies for gathering and analysing data in a study (Polit and Beck, 2010). The methods applied in this doctoral research are discussed in sections 2.4 to 2.6. Teddlie and Tashakkori (2009) expand on research **methods** as including:

> *"Specific strategies and procedures for implementing research design, including sampling, data collection, data analysis, and interpretation of the findings" (Teddlie and Tashakkori, 2009:21)*

In summary, a paradigm is a general world view, deriving from a philosophy. A research methodology is a wide approach resulting from the adopted paradigm and influencing the preferences for how the research processes will take shape. Lastly, research methods are the practical and specific strategies used in the conduction of the research (Teddlie and Tashakkori, 2009).

2.2 Research paradigms in social science

Three major paradigms exist in social and behavioural science: positivism (quantitative research), constructivism (qualitative research) and pragmatism (MMR). This doctoral study is grounded in the latter, applying and integrating both

quantitative and qualitative methods (see section 2.4.3). Positivism and constructivism are first briefly discussed (respectively in section 2.2.2 and 2.2.3). A more detailed description is then given of pragmatism (see section 2.2.4) as the underpinning paradigm to this doctoral research.

2.2.1 The three paradigms and their research orientations

As identified in section 2.1, each of the three research orientations (quantitative, qualitative and MMR) emerged from a particular paradigm that guides the nature and orientation of the research (Polit and Beck, 2010; Teddlie and Tashakkori, 2009). The paradigm underpinning the research shapes the approach to the methodology and methods in terms of the study purpose, the role of theory or logic in the study, the options on different study designs, sampling, data collection and analysis (Teddlie and Tashakkori, 2009).

Quantitative research is situated in (post)positivism and mainly focusses on numerical data and analysis. Qualitative oriented research emerges from constructivism or naturalism, identifying and applying e.g. narrative data and thematic analysis. MMR, often stated to stand between the previous two, is grounded in pragmatism. Whereas qualitative and quantitative research both have a long tradition in social and behavioural science, MMR only emerged during the last two decades (Teddlie and Tashakkori, 2009). This research orientation typically allows for complex phenomena to be explored from different angles (Teddlie and Tashakkori, 2009).

Placing the three research approaches on a continuum, ranging from purely qualitative towards purely quantitative oriented research, with mixed methods as an approach in the middle, resulted in Figure 8. The intersections formed by the Venn diagrams represent research undertaken with either a primarily qualitative

focus with some quantitative components (zone A) or a primarily quantitative with some qualitative elements (zone B).

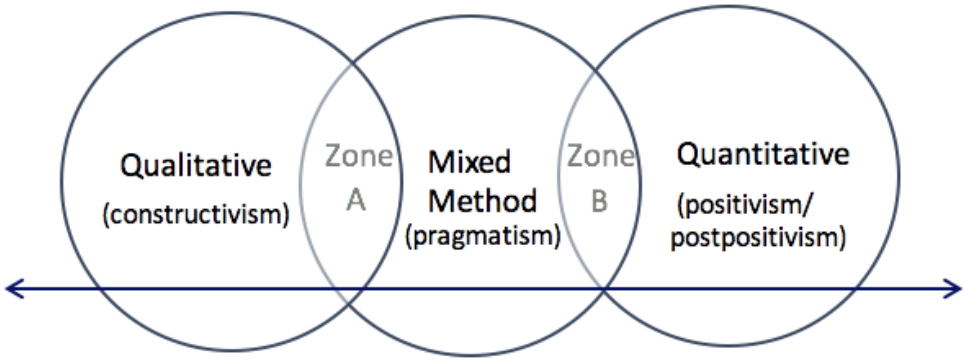


Figure 8: Qualitative, mixed method and quantitative research continuum (based on Teddlie and Tashakkori, 2009:28)

2.2.2 Positivism and quantitative research

Quantitative oriented social and behavioural science is typically interested in numerical data and (statistical) analysis. During the first half of the 20th century, with the exception (in some cases) of sociology, this was the dominant and relatively unquestioned methodological orientation (Teddlie and Tashakkori, 2009). Quantitative research is frequently used in correlational and experimental studies (Teddlie and Tashakkori, 2009). Within a positivist paradigm, quantitative researchers take the view that:

> *"social research should adopt scientific method, that this method is exemplified in the work of modern physicists, and that it consists of the rigorous testing of hypotheses by means of data that take the form of quantitative measurements" (Atkinson and Hammersley, 1994, cited in Teddlie and Tashakkori, 2009:5).*

Positivism looks to conduct research in an 'objective' way, ensuring researcher values or bias do not affect the way in which the research is conducted, nor the interpretation of the findings (Teddlie and Tashakkori, 2009).

Grounded in positivism, quantitative approaches often entail the formation of hypotheses (Teddlie and Tashakkori, 2009). For example, adopting a positivist approach to the current study would involve making falsifiable predictions about specific ways in which ICT could support care navigation in older people with multimorbidity. Hypotheses frequently derive from theories or previous research and often require a probability sample (see section 2.2.4.2) to answer the research question. A quantitative approach in this doctoral research would imply statistical analysis of numerical data to look for differences amongst groups (e.g. the PCN of those aged 55-65 years versus those aged 75 years and over). It would allow for deductive reasoning (from general ideas towards specific points) and be driven by theory and the current state of knowledge (Teddlie and Tashakkori, 2009). This was found to be a useful approach in relation to specific research questions about the structure of personal care networks (see section 2.4.3). However, the quantitative approach would not provide the nuanced information needed to answer the research questions around care navigation experience and/or navigation support (also see section 2.5.2). Thus, it was decided that a solely quantitative approach was not appropriate for this study.

Post-positivism takes into account several of the criticisms of positivism, most importantly they critique the ability of having one objective reality (Riggio, 2014). Research driven by post-positivism acknowledges that observations have error and that the reality cannot be known with certainty (Trochim, 2006). As such, post-positivists produce awareness of the complexity of practice and strive to be reflexive (Ryan, 2006).

2.2.3 Constructivism and qualitative research

Qualitative oriented research is principally interested in narrative data and analyses. Apart from the initial work by the Chicago School in the 1920s (Lutters and Ackerman, 1996), this type of research (e.g. ethnographic research) became mostly popular later in the 20th century questioning the quantitative tradition of research (Teddlie and Tashakkori, 2009). Being grounded in the constructivist paradigm, researchers believe that:

> *"They individually and collectively construct the meaning of a phenomenon under study" (Teddlie and Tashakkori, 2009:331).*

According to constructivists there is an element of 'subjectivity' to the reality they research. This derives from the idea that people give meaning to their experiences and seek understanding of the world they live and work in. These meanings and the construction of 'reality' emerges from interactions with others, hence why some commentators speak of social constructivism (Creswell, 2014). In other words, reality exists within a context and thus many constructions are possible (Polit and Beck, 2010). Epstein (2012) worded this as followed:

> *"The study of society involves a search not for facts, but rather for meaning" (Epstein, 2012:24).*

Constructivism moved away from the idea of 'objectivity' and looking for 'one truth or reality', as seen within positivism. Adopting constructivism as underpinning paradigm for this study would require thematic, narrative data (Teddlie and Tashakkori, 2009). Through analysis, meaning would be given to the data within their unique context (Silverman, 2011). For example, to gain an understanding of patients' care navigation experience and their requirements for a digital system to support their care navigation, data should be gathered from patients who had experience with navigating their care. As such, a purposive

sample would yield the most relevant data for this doctoral study (see sections 2.4.3 and 2.6.2). The subsidiary questions around roles and responsibilities of the actors in the PCN, the interaction processes within the PCN and the identification of design requirements would benefit from a qualitative approach. However, solely qualitative research would not have been able to capture the structural questions around the PCN (i.e. an overview of which actors are involved, also see sections 2.4.3 and 2.5).

2.2.4 The pragmatist paradigm and mixed method research

Pragmatism is often seen as moving away from the strict division between (post) positivism and constructivism (Polit and Beck, 2010; Spicer, 2012) and is defined by Tashakkori and Teddlie (2003) as:

> *"A deconstructive paradigm that debunks concepts such as 'truth' and 'reality' and focusses instead on 'what works' as the truth regarding the research question under investigation" (Teddlie and Tashakkori, 2009:342).*

Instead of focussing on methods, the emphasis in a pragmatic worldview is on the research problem itself. Starting from that point, pluralistic approaches to understand that problem are used (Creswell, 2014). This flows almost naturally into MMR, which is different to 'triangulation of methods'. The latter combines methods to cross-check the consistency of the research results, the former uses mixed methods to explore or address a research question from different angles (Spicer, 2012). It allows the researcher to apply diverse methods, have different assumptions, distinct forms of data collection and analysis and use different techniques and procedures in order to meet the needs and purposes of the research (Creswell, 2014). Apart from some exceptions, purely MMR can be seen as the intersection in a Venn diagram (Figure 8), created by the integration of quantitative and qualitative research. As such, mixed methodologists are

interested in both narrative and numeric data and their analysis, both deductive (see section 2.2.2) and inductive reasoning (from specific points toward general ideas), etc. (Creswell, 2014; Polit and Beck, 2010; Teddlie and Tashakkori, 2009). Mixed methodologists advocate for the use of "whatever methodological tools" (Teddlie and Tashakkori, 2009:7) are required to answer their research question. **MMR** has been defined as:

> *"Research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry" (Tashakkori and Creswell, 2007:4).*

Given the nature of the research question addressed in this PhD study, the limited available literature on the topic (see Chapter Three) and the limitations of the sole use of quantitative (see section 2.2.2) or qualitative research (see section 2.2.3), pragmatism was identified as the most suitable overarching approach for this study. In addition, the use of Social Network Analysis (SNA) (see section 2.4.3 and Chapter Four) required MMR (Scott and Carrington, 2011). Unlike the two other research traditions, MMR is less well known and only emerged as a research orientation during the last 20 years. Since MMR is the methodology chosen for this doctoral research, a more detailed discussion, including critiques on MMR, is provided in what follows.

2.2.4.1 Research designs in mixed method research

MMR has been conducted with explorative purposes on the one hand and for confirmation on the other hand (Teddlie and Tashakkori, 2009). Besides deciding on a paradigm and methodology surrounding the research, choices had to be made on the design or type of study that suited the research questions best (Creswell, 2014).

As MMR uses mixed methods, the sequence or the way in which the different methods in the study occur (i.e. study design) needs to be determined. Two main designs have been reported to guide MMR: 'sequential mixed design' and 'parallel mixed design' (Denzin and Lincoln, 2011). In the former, the mixed methods are applied in a chronological order. The latter implies that they overlap or are conducted simultaneously. Both designs are discussed in more detail in the next two paragraphs. This doctoral research was situated between the two traditional mixed method designs. Such adaptation to the traditional designs of MMR is not uncommon; pragmatism requires researchers to use methods and thus study designs, which best fit the research question (Teddlie and Tashakkori, 2009).

In a **parallel mixed design** the strands of the study appear either simultaneously or with overlap in time, hence the literature sometimes refers to this design as a concurrent or simultaneous design. The qualitative and quantitative phases of the study are planned and implemented usually to answer related aspects of the same basic research question (Teddlie and Tashakkori, 2009). The researcher integrates the collected data in the interpretation of the overall results (Creswell, 2014).

A **sequential mixed design** has the qualitative and quantitative stream of a study occurring in a chronological order. This results in questions or procedures emerging from one stream informing the next. The research questions in this design are often related to one another and can evolve as the study unfolds (Teddlie and Tashakkori, 2009). A sequential mixed method design can be explanatory or exploratory. In regard to the former, the quantitative strand of the research will be conducted first. After analysing the results, the qualitative strand takes place in order to explore and explain the results in more detail (Creswell, 2014). Exploratory sequential mixed methods research has the opposite structure, starting with the qualitative strand and exploring the views of participants. The data are then analysed and the information feeds into the second, quantitative, strand (Creswell, 2014).

Sequential and parallel mixed designs can then lay the foundation for more advanced mixed method strategies (e.g. quantitative or qualitative data are embedded within a larger design, the use of parallel or sequential strategies in tandem over time) (Creswell, 2014). In this doctoral research, a tranche of quantitative data was collected (questionnaire) and analysed, feeding into the design of the qualitative strand (semi-structured interviews). Interviews were then started, with the remainder of the quantitative data being collected and analysed concurrently with the interview strand. As such, there was an overlap in time (as seen in parallel mixed design), but the quantitative data from the questionnaire and SNA still fed into the qualitative strand (as seen in sequential mixed design).

2.2.4.2 Sampling and data collection in mixed method research

Two main types of sampling (probability and purposive) have dominated the field of social science. A third category (convenience sampling) often completes the list. However, as MMR has developed, this research orientation often has its own sampling techniques (i.e. a combination).

Probability samples (often used in quantitative research) generally aim to achieve representativeness by random selection. In contrast, **purposive sampling** (frequently used in qualitative research) selects a deliberate unit or subgroup in order to collect specific information. Finally, **convenience samples** are drawn because of accessibility and/or willingness to participate (Polit and Beck, 2010; Teddlie and Tashakkori, 2009). Depending on the focus and questions of the research, the researcher either wants to assure representativeness of the sample or focus more on the specific purpose the sample needs to serve.

As with many elements of MMR, the sampling techniques used in this research orientation often comprise an integration of both qualitative and quantitative strategies. To find this balance, combining qualitative and quantitative traits of sampling, the focus of mixed methods sampling strategies depends on the stage

to which the sampling applies (Teddlie and Tashakkori, 2009). According to the stage, the sample sizes might differ and the depth of information gathered varies (Teddlie and Tashakkori, 2009). The quantitative strand of this study (see section 2.4.3) collected numeric data from a larger number of people (across England) than the qualitative strand (within Lincolnshire). The latter collected narrative, in-depth information from a subsample drawn from the quantitative participants (see section 2.4.3). A detailed description of sampling for this PhD study is given in section 2.6.2. Here, the specifics of sampling, questionnaire development and topic guide construction are discussed and the reader is encouraged to keep this background in mind when interpreting the results of this study in chapters Four and Five.

2.2.4.3 Data analysis in mixed method research

Data analysis in MMR is arguably one of the biggest challenges (Teddlie and Tashakkori, 2009). As data are generally collected through different methods and tools (e.g. questionnaires and interviews), distinct types of data are produced (e.g. numerical codes and narratives) and require different methods for analysis (e.g. statistical or thematic analysis) in the same research project. Ensuring appropriate data synergy across the qualitative and quantitative strands in MMR has led to some commentators arguing that MMR relies on inference rather than rigorous analysis. Concerns have been raised about these inferences in MMR. In their discussion of data analysis integration, Teddlie and Tashakkori (2009) speak of **inferences** as:

> *"… either an outcome or a process of an investigation. As an outcome, inference is a conclusion or interpretation in response to a research question, made on the basis of the results of the data analysis. As a process it involves making sense out of the results of data analysis, which consists of a dynamic*

journey from ideas to data to results of data analysis, in an effort to make sense of the findings" (Teddlie and Tashakkori, 2009:336).

Using two different types of designs, underpinned by two distinct paradigms, to answer the same or closely related aspects of a research question requires careful practical considerations. Opponents of MMR suggest that the underlying philosophical views about the nature of the social world and the assumptions of qualitative and quantitative methods are fundamentally distinct (De Lisle, 2011; Spicer, 2012). According to critics, this makes such fusion of approaches incompatible (Ibid). However, other commentators argue that such differences are less determinative and fixed than they may seem at first sight. In other words, qualitative and quantitative methods may share more common ground in practice then would be initially suggested (Spicer, 2012).

Regardless of these different opinions, at the stage of data analysis, the pivotal action in MMR is to ensure that the data drawn from the different paradigms can be appropriately integrated. This requires thorough planning and consideration of how these data will be integrated. Rather than 'just' analysing the questionnaire and interview data, this study strived to have both types of data complement one another. To optimise the process of data integration, the **Integrative Framework for Inference Quality** (Appendix 3) as presented by Teddlie and Tashakkori (2009) was initially reviewed. This has been described as:

"A framework for assessing and improving the quality and transferability of inferences in research and incorporating quality indicators/audits from qualitative and quantitative research traditions" (Teddlie and Tashakkori, 2009:337).

The *'Integrative Framework for Inference Quality'* (also see section 2.5.2.3) is only one strategy to support multi-method researchers in the crucial task of integration. Ideally, quantitative and qualitative analyses are carried out in such a

way that they become interdependent. Findings from a MMR seek to produce something that is greater than the sum of the parts (MacKenzie et al., 2014). To assure this outcome, true integration of both qualitative and quantitative data took place through the application of SNA and framework analysis (see section 2.5.2 and Chapter Four) as well as in the development of personas (see section 2.5.3 and Chapter Five).

2.3 Research at the intersection of care and technology

This doctoral study took place at the intersection of care and technology. With research at this intersection increasing, it has become its own field of research. The changes in today's society, as discussed in Chapter One, further contributed to a rise in studies on care technology in older people (also see Chapter Five). Increasingly detailed guidelines are produced to advise, for example, on interface design for older people (e.g. Fisk et al., 2009). Guidelines that support researchers in carrying out their own usability studies are however scant (Dickinson et al., 2007).

Whereas health and social care have a long history of research in the context of older people, this is a relatively new area in the field of computer sciences. Collecting data from older people might require modifications of the traditional computer science research methods or, certain methods may be less appropriate for use in this population (Dickinson et al., 2007; Eisma et al., 2004).

2.3.1 Older versus younger study participants

Whilst it is recognised that older people are not a heterogeneous population (Moser et al., 2012), the differences in ageing are significant. Compared to the group of participants with which computer scientists and HCI researchers are familiar (i.e. students or young people), older people, for example, demonstrate a

wider range of educational experiences. In addition, many of them do not live close to research institutions, are unfamiliar with university layouts and/or experience mobility issues (Dickinson et al., 2007). Older participants also vary greatly in the amount of free time and flexibility they have. Some have very few obligations, whilst others have a number of roles or responsibilities (e.g. unpaid carer or volunteer) (Dickinson et al., 2007).

Age-related changes (also see section 5.1.3) do not only interfere with older people's interaction with ICT, they can also impact on the collection of data. For example, a decline in auditory perception can make hearing study instructions difficult; reading the instructions could be burdensome when the participant has visual impairments; loss of fine motor control could make precise tasks (e.g. using a mouse) challenging; and changes in memory and cognition can affect the participant when s/he has to follow steps during an experiment (Dickinson et al., 2007). In addition, it has been demonstrated that older people are anxious or fearful about memory changes (Dickinson et al., 2007). They will need reassurance that errors are normal and to be expected (Dickinson et al., 2007). Different topic areas could be sensitive depending on someone's age or personal situation. Older people are for example found to be less willing to talk about issues such as social isolation (Eisma et al., 2004). Sensitive topics might also challenge the older person's identity as an independent person and thus careful consideration of the wording of questions is necessary. At the same time, researchers need to be aware of the possibility that an older person is participating because s/he feels lonely (Eisma et al., 2004).

2.3.2 Collecting HCI data in older people

In terms of collecting data, regularly used methods might pose specific challenges for older people. For example, the use of *focus groups* has been proven difficult when impairments are present or owing to a reduced attention span (Eisma et al.,

2004; Malik and Edwards, 2008). A further challenge relates to cultural differences (in this case often generational differences); asking older people to undertake *participatory activities* to help design, for example a mobile phone, resulted in a design that merely reflected researcher opinions (i.e. expectancy bias or experimenter effect) (Malik and Edwards, 2008). Since older people are often unfamiliar with 'experimental' settings they might also try to involve the facilitator or researcher in the experiment (Dickinson et al., 2007) which could result in a response bias. The application of *user diaries* in experimental studies has also shown difficulties. Learning and understanding the process of experimental studies that involve ICT is already demanding. Older participants often do not have the energy, attention or time left to complete the diaries (Dickinson et al., 2007). When they do, it tends to happen after completion of the tasks and the recall of events might be limited. Generally, older participants need repetition of the task before they can accurately remember the process (Dickinson et al., 2007).

Changes in sight, hearing and short term memory could similarly complicate accurate *self-reporting* (e.g. questionnaires) (Eisma et al., 2004). However, a recent study pointed out higher accuracy in self-reporting among older people than younger individuals (Ning et al., 2016). Collecting data by letting participants *'think aloud'* as they go through the tasks, might not be as effective when compared to using such a method with younger cohorts. Thinking aloud interferes with the completion of tasks, especially when they are carried out in unfamiliar interfaces (Dickinson et al., 2007). Dickinson et al. (2005) used a developed version of the 'think aloud' method to understand participant perceptions. Allowing older participants to look at a web page first and then re-present it when they are asked to describe it, resulted in higher quality data (Dickinson et al.,2005).

When conducting face-to-face *interviews*, researchers need to be aware that the duration of the interviews might need last minute, onsite adjustments (Eisma et al., 2004). Older adults might suffer from multiple conditions or lower energy

levels and long interviews could be too exhausting. Telephone interviews leave the older participant with fewer non-verbal cues, which could be a disadvantage for those with hearing problems (Eisma et al., 2004; Malik and Edwards, 2008). Sometimes these issues can be resolved by providing more time, explanation and reassurance. However, researchers need to be aware that not addressing these differences can lead to frustration and confusion. As a result, older participants might withdraw from the study (Dickinson et al., 2007).

2.4 Overall research design of the doctoral study

2.4.1 Conceptual Framework of the study

Prior to designing the research, a number of supporting theories were explored and considered. There was a range of methodological guidance that could have applied to this study. Examples included The Medical Research Council's guidance for the development and evaluation of complex interventions (Craig et al., 2006) and the Intervention Mapping Protocol (IMP) (Bartholomew et al., 2011). These did not necessarily prescribe a linear or even cyclical sequence, but provided an overview of key activities (building blocks) that could shape the research (Craig et al., 2006). As such, they were used as an inspiration for the design of this multiphase PhD study and led to the four main work streams as described in section 2.4.3. However, the core focus for this study was on the three selected theories discussed below.

Person-centred care (also see Chapter One, section 1.1.3), patient empowerment (also see section 1.1.3) and user-centred design were the three theories that provided extra lenses to this research. These three theories could, and were developed to, stand in their own right. Within this particular research the elements from each were found to be strongly interlinked (Figure 9, p.74).

2.4.1.1 Person-centred care

A detailed discussion of person-centred care can be found in Chapter One (see section 1.1.3). In summary, person-centred care is care delivered and organised *in partnership* with the patient (and his/her relatives) and around the patient. It focusses on the patient as a 'whole', his/her needs and his/her strengths. Four main principles underpin this care model, namely, (1) treating people with dignity, respect and compassion, (2) deliver coordinated and (3) offer personalised care, support or treatment, and (4) enable patients to live independent and fulfilling lives (The Health Foundation, 2014).

2.4.1.2 Patient empowerment

If we are to facilitate person-centred care, rather than disease-oriented care (see Chapter One), patients need to become an active player in their care plan (also see section 1.1.3). They should be perceived as experts in how they manage their LTCs and care on daily bases and encouraged to take an active role in setting out their care plan. To achieve this, patients need to be provided and supported with tools to help them in this role; they need to be empowered. Patient empowerment is a process as much as it is an outcome. Whilst various descriptions of patient empowerment have been brought forward, a clear definition is lacking. Bravo et al. (2015) published a conceptual framework for patient empowerment, indicating key components and relationships alongside other concepts such as self-management. It can be argued that patient empowerment directly links to person-centred care as it is one of the four key principles for this care model (see section 1.1.3) (The Health Foundation, 2015). Patients are empowered when they are supported in their development of knowledge, skills and confidence to effectively manage (including decision making) their own health (The Health Foundation, 2015). The WHO defined **patient empowerment** as:

"A process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation" (WHO, 2009).

2.4.1.3 User-centred design

During the first European Conference on Patient Empowerment it was noted that new technology can support patient empowerment and person-centred care (WHO, 2012). However, 'a tool' will not provide the 'whole answer', especially if that 'tool' is designed with limited input from the intended end-user (Wachter, 2016; WHO, 2012). Four steps were mentioned at this conference to move patient empowerment forward. Firstly, it was noted to *"continue the development of the notion of co-producing and defining more clearly what is meant and how outcomes can be measured more clearly"* (WHO, 2012). Secondly, to *"take advantage of opportunities that are available, ensuring that patient empowerment is part of other political agendas that are underway"* (Ibid). The other two steps at the conference were specifically around the use of technology supporting patient empowerment and, more widely, person-centred care. It was emphasised that we need to *"shape systems and technology, in the direction of collaboration and co-production between patients and the health system"* and *"use technological and other means to increase knowledge generation and exchange from patient to patient"* (WHO, 2012).

In the same way that person-centred care puts the patient at the centre of care (The Health Foundation, 2014), user-centred design places the users at the core of the product or system development (Wright and McCarthy, 2010). This requirement of giving end-users a voice throughout the design and development process is the core motivation of user-centred design (UCD) (Wilcox et al., 2010). In this doctoral study, those people aged 55 years or older and living with

multimorbidity are at the centre of any and all processes. As such, UCD can be understood as facilitating person-centred care through design activities, using empowerment both as a process and an outcome. In this study, the three underpinning theories (i.e. patient-centred care, patient empowerment and UCD) were brought together, which led to the development of a new conceptual framework: patient-centred design (Figure 9).

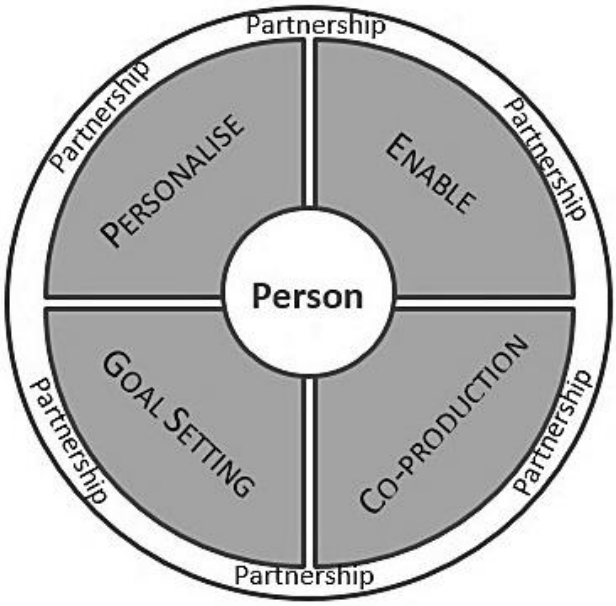


Figure 9: Framework of Patient-Centred Design

2.4.2 Patient-centred design

Previous research in the design of technology within the care setting has, for example, explored behavioural change frameworks for the development of interventions (Michie et al., 2011) and the use of experience based co-design to improve service development (Tsianakas et al., 2012). At the time of conducting this study, no existing frameworks had linked the three complementary theories discussed above in the context of care and technology. They were found compatible in this particular study context, providing a conceptual basis for thinking about the design of technology in the care setting.

In partnership with users (i.e. both in terms of care services and technology) the aim is to design and deliver care (whether or not supported by technology) that is tailored to their needs (**personalised**). Users are experts in their life, their experience within the care system and technology, their needs, and their requirements for design. Both care itself and technology designed to support care, are intended to **enable** users to build on their strengths and capabilities. This also means that one needs to start from what users are 'able' to do (asset-based approach) instead of what they can no longer do (needs-based approach). Moreover, enabling users to sustain or improve their care through technology demands that users are able to use and apply those technological applications built to support their care navigation. By designing these applications in partnership, users are empowered to voice what they want the system to do for them, what their needs and **goals** are and how they currently bridge that gap. The process of **co-producing** (both an electronic system and care services) supports the idea of empowerment and at the same time the end result is meant to empower the user; making sure they have positive experiences by living with technology instead of just using it.

The adoption of this conceptual framework in which the person (i.e. patient/user) is given a central position, influenced the methods used in this doctoral study. By placing the patient central to the design process for an ICT tool to support care navigation in older people with multimorbidity, it demanded a patient perspective throughout the thesis. This resulted in the literature review focussing on patients' perspectives of care navigation, the social network analysis (see next section) exploring the PCN from a patient perspective (egocentric) instead of a systems approach (sociocentric) and design requirements being developed according to patients' experiences, needs and goals. To gather data on the latter, the patient-centred design framework also informed the construction of the topic guide for

semi-structured interviews. The next sections outline the details of the research questions and methods used to address the study's objectives.

2.4.3 Overview of the design of the study

The overall mixed method design of this PhD study (Figure 10) addressed the topic of how ICT could support older people with multimorbidity in their navigation through the care system. It had explorative as well as confirmatory purposes for which a multiphase study was designed. Each phase was to answer concrete subsidiary research questions and to reach specific aims. This resulted in the development of four main work streams: literature synthesis, social network analysis, semi-structured interviews and writing design requirements. By combining work stream two (SNA) and three (semi-structured interviews), and thus integrating the data, the four work streams were structured into three stages.

The three stages correspond with the three objectives (see section 1.2.3.1) set for this study:

1 Synthesise the literature on care navigation among older people with multimorbidity from a patient perspective (see Chapter Three).

2 Analyse and visualise the structures of and interactions in the personal care network (PCN) of older people with multimorbidity and gain an understanding of their experiences of navigating their PCNs (see Chapter Four).

3 Identify elements for improvement in care navigation among older people with multimorbidity and deliver design requirements for the development of an ICT tool to support this population in their navigation through the care network (See Chapter Five).

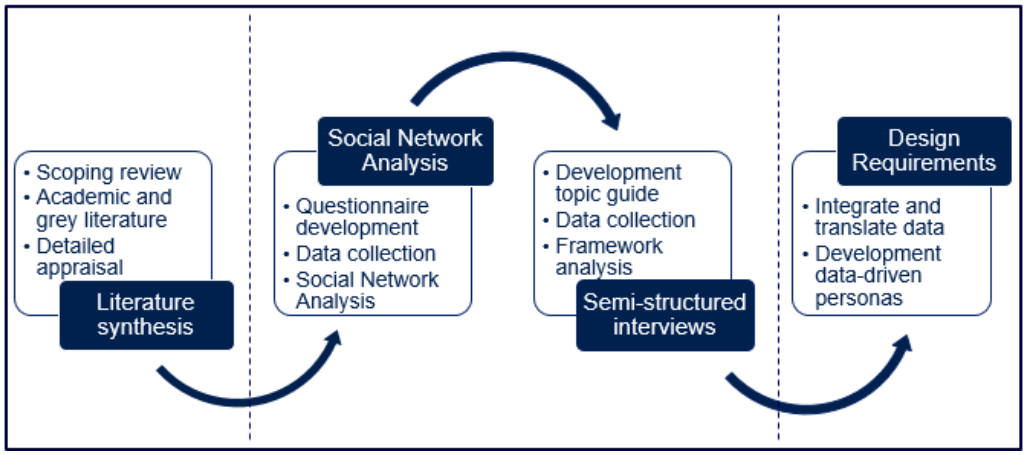


Figure 10: Design of PhD study

The first stage of the study, addressing the first objective, was set up to answer the question *'What does the literature regarding care network/system navigation in the setting of older people with multiple morbidities tell us?'*. Looking from a patients' perspective, the focus of the literature synthesis was on literature involving care navigation in older people with multimorbidity, patients' experiences and potential ways to support this (also see section 2.5.1 and Chapter Three). As such, the first stage of the study aimed to identify the current knowledge and gaps around this topic (see section 3.4). These gaps then formed the foundation for the second and third stage of the study.

The aim of the second stage, relating to the second objective, of the study was twofold. In the first instance this phase aimed to generate insight into *'What does the care network of older people with multimorbidity look like from a patients' perspective?'* Through the use of a self-completion, structured questionnaire, data were gathered across England of people aged 55 years and over with at least two LTCs. The information from this quantitative strand intended to gain an understanding of **who** was found to be important in the PCN according to patients and who they were in **contact** with in terms of care provision (also see section 2.5.2.1 and Chapter Four). SNA is a method used to gain an understanding of

characteristics of relationships such as frequency, type and direction of communication among people in the network (Scott and Carrington, 2011). A substantive discussion of SNA is given in Chapter Four. SNA was used to visualise this information, thus displaying the PCN's of older people with multimorbidity, and statistical testing was undertaken to address the following subsidiary questions:

a) Which actors are involved in the PCN of older people with multimorbidity and from which care domain (social care in the community, health care in the community, health care in the hospital and informal care)?
b) Does this structure of the PCN differ according to the number of LTCs, age and sex?
c) Why are these actors present in the PCN of older people with multimorbidity?
d) Does this reason for involvement differ according to the number of LTCs, age and sex?
e) How are actors involved in the PCN of older people with multimorbidity?

Secondly, this stage of the study involved conducting semi-structured interviews. An interview topic guide was constructed (see section 2.6.1.2) based on the study objectives and the patient-centred design framework (see section 2.4.2). The qualitative data were to complete the picture of the PCN by providing insights into **why** the actors were present in the PCN. Data in this qualitative strand enriched the quantitative data by providing in-depth and nuanced information on the interactions within participants' PCN, **how** navigation through this network occurred and what could be **improved** (also see section 2.5.2.2, Chapters Four and Five).

In the third stage, this study built on the quantitative and qualitative data collected in the second phase. The purpose here was to focus on patients' opinions of how the different actors in the PCN interacted, their experiences of PCN navigation, their ideas for improvement and how ICT could support such improvements. As such, this stage particularly looked for information on *'how does the care network of older people with multimorbidity function in the opinion of the patients?'* and *'How can ICT support patients in the tasks of navigating and interacting in their care network?'* The integrated data were then translated into design requirements (i.e. personas) for the development of a digital care navigation support tool (also see section 2.5.3 and Chapter Five). This third stage in the study responded to the third objective.

2.5 Methodological considerations for the study

Throughout this multiphase study, numeric as well as narrative data were collected in separate, but connected, strands as suggested for MMR (Spicer, 2012; Teddlie and Tashakkori, 2009). Data were collected through the literature (scoping review – see Chapter Three) and from people living in England, who had been diagnosed with two or more LTCs and were 55 years or older (see Chapters Four and Five). Although the term 'older people' in health and social care research often refers to people aged 65 years or over, this tends to be different in the fields of technology (design) and computer science (Wagner et al., 2010). To ensure all fields involved in this study could be encompassed, the initial exploration of the literature at the start of this doctoral research embedded and the demographics of the post-World War II population structure in the UK reflected, it was decided to include people aged 55 years or over. In addition, the absolute numbers of people diagnosed with a range of LTCs are higher among those aged 45-65 years than the older-old (Barnett et al., 2012; Fortin at al., 2007; NHS England, 2013a)

and daily activities are more frequently limited by disability or health problem in those aged 50-64 years in England (Morse, 2014).

The rationale to apply a patient perspective to care navigation rather than focussing on the care system or providers was twofold. Firstly, it was decided that patients are one of the few 'constants' in care. Care systems for example are subject to change based on knowledge and governmental policy requirements (Taylor-Goodby, 2012). Providers (e.g. GP or social care services) could have been another focus in this study, however previous research (e.g. Yao et al., 2012) has emphasised that care navigation should begin focussing on patients rather than the surrounding health and care systems. In addition, the underpinning theories around patient empowerment, patient-centred care and user-centred design and thus the conceptual framework (see section 2.4.3), naturally demanded a patient focus in this study.

2.5.1 Phase one: Literature Synthesis

To review the literature, different approaches could have been used e.g. meta-analysis, rapid reviews, narrative reviews, research synthesis, structured reviews, etc. One of the most applied approaches is that of a systematic review. Systematic reviews typically asses review literature on a well-defined topic, focussing on specific research designs and addressing a concrete research question (Arksey and O'Malley, 2005; Higgins and Green, 2011). In contrast, scoping reviews, tend to use a broader approach or cover a wider topic with many different study designs involved (Arksey and O'Malley, 2005). In that respect, **scoping reviews**:

> *"aim to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as stand-alone projects in their own right, especially when an area is complex or has*

not been reviewed comprehensively before" (Mays et al., 2001, cited in Hidalgo Landa et al., 2011:46).

Arksey and O'Malley (2005) suggest the use of scoping reviews when the aim is to: comprehensively cover the available literature in breadth; examine the extent, range and nature of research activities; determine the value of undertaking a full systematic review; summarise and disseminate research findings; and identify research gaps in the current literature.

Although scoping reviews tend to focus less on the quality of the studies involved in the review (Arksey and O'Malley, 2005) their purpose was found particularly suitable for the aim of this study's literature synthesis: bringing together the available literature on care navigation in older people with multimorbidity. Within this broad approach, the focus was on the patient's perspective in terms of care navigation when diagnosed with multimorbidity. Although it was acknowledged that the literature on single LTCs could provide information on care navigation, multimorbidity was the core search term for the scoping review. The core rationale for this was the finding drawn from previous literature (see Chapter One) that emphasised the unique challenges posed by managing multiple LTCs as opposed to single LTCs. The focus of this doctoral research was to explore, assess and measure the differential care needs (often outside and conflicting with normal care pathways) and any necessarily innovative routes to care.

2.5.2 Phase two: Social Network Analysis and Framework Analysis

Phase two of the study intended to address the gaps in knowledge as identified through the scoping review. Quantitative data were collected through a structured questionnaire (also see Chapter Four), focussing on the lay-out of the care network that surrounds older people with multimorbidity, i.e. their personal care network (PCN). The collection and analysis of semi-structured interviews

(qualitative data) allowed for the exploration of roles and responsibilities within the PCN.

2.5.2.1 Social Network Questionnaires

Questionnaires have been used frequently in social and behavioural sciences (Scott and Carrington, 2011). In most cases, structured questionnaires (differentiating from structured interviews) have been self-administered by the individual (Polit and Beck, 2010). Questionnaires typically gather information about people's actions, knowledge, intentions, opinions and attitudes (Polit and Beck, 2010). With regard to collecting network data, questionnaires have been reported useful for the assessment of connections and relationships between people or social actors (Scott and Carrington, 2011). Depending on the position from which one looks at a network (or indeed the connections within the network), the content of network questionnaires has differed (also see Chapter Four). Whereas 'whole network' studies (sociocentric network analysis) intend to measure structures of a particular social group as a collective, 'egocentric' studies have typically been more limited in their focus by looking at relationships of one focal unit or actor (Scott and Carrington, 2011) (see section 4.1.4 for details on SNA). It was the latter that was adopted here, given it aligned with the study's focus on the patient's perspective.

Structured questionnaires for SNA

Very few examples of validated (or indeed, non-validated) questionnaires for social network data were found at the start of this study (e.g. Frank, 2000 and Durant-Law, 2006). The majority of the existing questionnaires were designed for sociocentric network analysis (see section 4.1.4), analysing, for example, relationships between employees in companies, and were not deemed suitable or relevant for the egocentric research demanded by this study (see section 4.1.4). As such, a new questionnaire needed to be developed based on the research

objective of the second phase of the study (see Table 1) and the findings from the scoping review (first phase of the study).

Since it was known beforehand which type of information was needed to address the question of *'who is involved in the PCN of older people with multimorbidity'* (i.e. information on the different carers involved), a structured questionnaire was found the most suitable option (Polit and Beck, 2010). To reach as many potential participants as possible, the questionnaire was available online and in hardcopy (Evans and Mathur, 2005); the latter also ensuring appropriate accessibility to older respondents with visual or communication difficulties.

Sampling would influence the inferences made about network properties (Wasserman, 1994; Scott and Carrington, 2011). Therefore, clarity was needed about which data were required to answer the research question and, in consequence, the most suitable sampling method (Scott and Carrington, 2011).

Collecting egocentric questionnaire data

Network data can be collected in various ways, e.g., interviews, observations, questionnaires, archives, or a combination of these (Scott and Carrington, 2011). In the first instance it was not necessarily as much about the 'method' used than it was about the instrument(s) and the purpose of the data collection. Over the years SNA developed tools that served different purposes in egocentric networks (Table 2).

Table 2: Instruments to measure egocentric networks

INSTRUMENT	PURPOSE	EXAMPLE
NAME GENERATORS	Gathering data on individual relationships.	"From time to time, most patients discuss important matters regarding their health with other people. Looking back over the last 3 months, who are the people with whom you discussed matters important to you?"
NAME INTERPRETERS	Collecting information on attributes of the alters, on properties of ego alter ties or information on relationships amongst the alters.	"Is [name] from Asian, Black, Hispanic, White or other origin?"
GLOBAL QUESTIONS	Used for summary assessment of some ego network properties	"Do you have good friends? If yes, about how many good friends do you have?"
POSITION GENERATORS	Measuring respondent's relationships to particular types of alters or other types of social locations, e.g. ethnic groups.	"Amongst your relatives, friends or acquaintances, are there people who have the following jobs?" For each job the respondent will get the question: "What is his/her relationship with you?"
RESOURCE GENERATORS	Multiple-item instruments used to assess the access to social resources directly by asking respondents if they	"Do you know anyone who… a) can drive a van, b) can fix a car, c)…?"

INSTRUMENT	PURPOSE	EXAMPLE
	have personal contact with anyone who possesses a certain asset or capability.	
SUPPORT SCALES	Multiple-item instruments to elicit reports about the support received to be available or the support actually received.	"From time to time, people ask for help with small jobs in the house. Who are the people you usually ask for this kind of help?"

By identifying the data needed to answer the research question, tools were selected and brought together into a coherent instrument. The type of instrument was then used to guide the decision on which method to apply in order to optimise data collection. After careful consideration and discussion with experts in SNA, it was decided that two instruments were needed to collect network data for this study: questionnaires and semi-structured interviews. Each would serve a slightly different purpose. Questionnaire data were needed to help answer the question of 'who' was involved in the PCN and to some extent 'why' they were. However, they would not give in-depth information on the latter, nor on 'how' they are involved or in 'what' way the network functions. Semi-structured interviews were put in place to address these aspects and enrich the data deriving from the questionnaire (see section 2.5.2.2).

The study questionnaire was designed with the intention to provide quantitative information for the PCN in older people with multimorbidity. The majority of questions were close-ended, allowing comparison of the specific data. In the study of egocentric networks, one of the frequently used tools for data collection are **name generators**. These are questions used to elicit data on the individual relationships in a network. They look for the 'role' in relations (e.g. friends or neighbours), aspects of relational forms (e.g. closeness or frequency of contact)

and specific types of resource transfer or exchange (e.g. information). Depending on the research question, different tools can be preferred or added. **Name interpreters**, for example, can follow name generator questions to gather more information on attributes (e.g. race and age) of alters, property information of the ego alter ties (e.g. emotional closeness) or information on relationships among alters themselves. Other examples of common tools in (egocentric) SNA are given in Table 2.

Further details on sampling, the process of data collection as well as the development and pilot testing of the questionnaire can be found in section 2.6. The analysis process and results are outlined in Chapter Four.

2.5.2.2 Semi-structured interviews

Although interviews could be used as stand-alone method for data collection (Lazar et al., 2010; Silverman, 2011), in this study they added richness and depth to the data and complemented the questionnaire data by providing information on patients' experiences of interactions in the PCN. In other words, the questionnaires collected data on 'who' is involved, whereas the interviews focused on 'what' that involvement entailed and 'how' those people were involved.

Decision on the structure of interviews

Regardless of the way in which interviews are used, a decision had to be made in terms of the type of interview that would be most suitable. Three main types of interviews have been reported. The terms used to refer to these types differed across the literature, but incorporated: unstructured, semi-structured and structured interviews (Lazar et al., 2010; Preece et al., 2015). The latter comprised a set of questions being asked in a specific order. All participants would be asked the same set of questions, in exactly the same order. Unstructured interviews

would be the complete opposite. Although the area of enquiry would be clear, open questions would be posed to which the answers could go in any direction; the participant interprets the question in the light of their own experience and thus responses would naturally differ greatly. Dependent on those areas the participant discussed, the interviewer would then ask additional questions (prompts) deriving from the content of the interview. Thirdly, semi-structured interviews would use a 'guide' that included questions and topics that must be covered during the interview, but the order in which these are discussed varied depending on the flow of the interview. These types of interviews were generally used in research where one sought in-depth information or thorough understanding of a topic (Lazar et al., 2010). To respond to the research question of 'why the actors indicated in the questionnaire were involved in patients' PCN', an open interview structure was necessary to ensure the experiences of the 'actors' could be appropriately explored.

Decision on the type of interviews

The topic guide for the semi-structured interviews in this study was developed based on the literature, the initial findings from the social network questionnaire and the patient-centred design framework (see section 2.4.2). Sections 2.6.1.2 and 2.6.2 detail the development of the topic guide and the process of data collection. Chapter Four reports on the analysis and results of the interviews. The topic guide was intended to be used during face-to-face interviews, however the possibility of conducting telephone interviews was not excluded. The rationale behind the decision of face-to-face interviews is outlined below.

Traditionally two main interview techniques dominated the field, namely face-to-face interviews and telephone interviews. However, as new communication technologies expanded, two additional techniques emerged, i.e. e-mail and chat boxes (also see Table 3) (McCoyd and Kerson, 2006; Opdenakker, 2006). Not only

do these techniques differ in terms of 'location', they also have considerable differences in terms of 'time' (Opdenakker, 2006).

Table 3: Characteristics of different interview techniques (based on Opdenakker, 2006)

CHARACTERISTICS				
Technique	Synchronous in time	Asynchronous in time	Synchronous in location	Asynchronous in location
FACE-TO-FACE	X		X	
TELEPHONE	X			X
E-MAIL		X		X
CHAT BOX	X			X

The differences between techniques would inevitably bring along some advantages and disadvantages. Techniques that are synchronous in time have, for instance, almost no 'delay' between the question asked and the answer given. Depending on the purpose and nature of the research, this can either be an advantage or a disadvantage. Having a 'quick' turnaround between questions and answers can yield spontaneous and often rich data. However, this can also provide more 'noise' in the answers, i.e. irrelevant information, or make the interviewee feel pressured to answer immediately. Interviews carried out synchronous in space hold for example the risk of 'interviewer effects' (e.g. non-verbal communication by the interviewer reflecting a negative attitude from the

interviewer may lead the participant to adjust their answer), but on the other hand allows the interviewer to pick up on social cues such as non-verbal behaviour from the participant (also see Table 4) (Opdenakker, 2006).

Table 4: General (dis)advantages of interview techniques (based on Opdenakker, 2006)

	ADVANTAGES	**DISADVANTAGES**
FACE-TO-FACE	• Social cues can be picked up • No delay between questions and answers • Word for word recording • Possibility to facilitate the atmosphere of the interview	• Interviewer effects • Double attention needed • Time consuming for transcription • Use of resources
TELEPHONE	• Extended access to participants (e.g. geographical) • No delay between questions and answers • Word for word recording of the interview	• Reduction in social cues that can be picked up • More difficult to facilitate the atmosphere of the interview • Others might be present without the interviewer's knowledge • Double attention needed • Time consuming for transcription
E-MAIL	• Extended access to participants (e.g. geographical) • Interview transcription has no 'noise' • Questions are posed and answered at a time convenient for the parties involved • Reduced costs • Interview transcript is directly downloadable • Answers might be more reflective due to 'time'	• No social cues can be picked up. • Delay between questions and answers • No spontaneous responses • Requires familiarity with technology

	ADVANTAGES	DISADVANTAGES
CHAT BOX	• Extended access to participants (e.g. geographical) • Increased feeling of anonymity • Cost and time savings • Ability and time to add questions • No disturbing noises on recording • Record is directly downloadable	• No social cues can be picked up • Often double time needed to reach 'depth' in interview • No possibility to 'facilitate' the interview atmosphere • Risks of miscommunication • Requires familiarity with technology • Visible to other members in the chat box

No technique is perfect and a particular disadvantage of one can be an advantage of the same technique in another study, depending on the purpose of the interview. The decision comes down to the aim of the research and the population under study. Table 4 provided an overview of some of these common considerations in deciding which way the interview is best conducted.

Whilst a big advantage of chat box and/or e-mail lays in their ability to reach a wider group of participants, without increases in costs or time spent transcribing (McCoyd and Kerson, 2006; Opdenakker, 2006), the opposite might be true for some of the older people that I had hoped would participate in this study. Although chat boxes and e-mails did not pose geographical limits, both limited the group of participants to those who were familiar with and had frequent access to a computer. The latter might not always be the case in older people and they could be 'put off' by these techniques as opposed to the conventional approaches (also see section 2.3). In the design of this study, face-to-face interviews were preferred over telephone interviews. Even though both methods were found suitable, it was anticipated that face-to-face interviews would allow more depth, probing based on visual cues, less misinterpretations and the ability of the participant to 'chat' openly without any other distractions (McCoyd and Kerson, 2006; Opdenakker,

2006). However, if preferred by the patient, telephone interviews were provided as an option.

Decision on the type of analysis

As this doctoral study was underpinned by the patient-centred design framework (see section 2.4.2), the analysis of the interviews was guided by the six elements present in the framework (i.e. partnership, enablement of the person, personalisation of the tool and care, goal setting of the person and co-production of care and technology alongside the individual). As such, interviews were analysed bearing in mind these six components and the research questions (see section 2.4.3). In addition, the interview data needed to be linked to the questionnaire data to reach optimal integration of the data as required in MMR (see section 2.2.4.3). For this purpose, amongst other reasons such as its transparency and systematic approach (see section 4.2.2), framework analysis was selected as the most suitable method for analysis of the semi-structured interviews. For this study, the framework for analysis was based on the patient-centred design framework (section 2.4.2), the research objectives (2.4.3) and the topic guide (2.6.1.2). Interviews were analysed by initial line-by-line coding of the transcripts, categorisation of these codes and mapping of the categories onto the themes of the framework for analysis. More detail of this process is given in Chapter Four.

2.5.2.3 Inference quality – data integration

The assessment of the quality of inferences (see section 2.2.4.3) in MMR can be challenging (Teddlie and Tashakkori, 2009). **Inference quality** refers to:

> *"The extent to which the interpretations and conclusions made on the basis of the results meet the professional standards of validity, rigor, credibility, and acceptability" (Teddlie and Tashakkori, 2009:336).*

Crucial for MMR is to reduce the gap between inferences made based on the quantitative data and those made based on the qualitative data. In other words, to integrate the two sets of inferences generated by the two strands in the study (Teddlie and Tashakkori, 2009). All of this comes together in the term **integrative efficacy** which has been described as:

> *"The degree to which inferences made in each strand of a mixed method study are effectively integrated into a theoretically consistent meta-inference" (Teddlie and Tashakkori, 2009:337).*

Rather than having qualitative and quantitative research and analysis as 'stand alones' and then combined in a study (Creswell and Tashakkori, 2007), it is only through comparing and contrasting, modifying one on the base of the other, that true MMR is achieved (Teddlie and Tashakkori, 2009). Three measures were taken to increase integration of the data in this study. Firstly, the use of SNA allowed for comparisons and integration of the questionnaire and interview data (see section 2.5). Secondly, framework analysis lent itself to connect the different types of data and look for emerging themes (a description of and details on the process for framework analysis are given in section 4.2.2). Thirdly, phase three of the study (see next section) relied on the integrated data to formulate design requirements.

2.5.3 Phase three: Development of data-driven personas

Both the quantitative and qualitative strand in phase two were fed into the third phase of the study (see Chapter Five). This phase aimed to present findings on patients' experience in care navigation and particularly on which elements needed to be borne in mind when designing an ICT tool to support care navigation in this study population. Again, the development of design requirements was guided by the underpinning conceptual framework of Patient-Centred-Design. The design requirements resulting from this doctoral research are grounded in data deriving

from patients (partnership and co-production) and show those goals important to older people with multimorbidity in their care navigation.

The third phase of the study integrated and translated the data into design requirements. To communicate the design requirements resulting from this study, four data-driven personas were created. Since the decision to use personas was based on the data that emerged from this study, the process of their development is discussed in Chapter Five.

2.5.4 Software used to support data analysis

It was decided that five types of software were needed to support data analysis in this study. In the first instance SPSS Statistics V22 (IBM Corp) was used to facilitate descriptive analysis and statistical testing (i.e. logistic regressions, correlations and ANOVA). Secondly, Gephi 0.9.1 (Mathieu et al., 2009) was used as visualisation and exploration software assisting SNA. Thirdly, framework analysis was applied for the interview data and supported by Excel and NVivo version 10. Finally, the creation of data-driven personas made use of Xtensio (2016), a user experience platform for the creation of personas.

2.6 Data collection and sampling

This section discusses the data collection and sampling techniques for this doctoral study. The analysis process (SNA and framework analysis) can be found in Chapter Four with the results relating to the PCN structure also discussed in that chapter. Chapter Five discusses the formation of data-driven personas and their results in relation to care navigation experiences and improvements.

2.6.1 Data collection for this study

2.6.1.1 Collecting egocentric network data

Questionnaire construction

A self-administered questionnaire was selected to collect egocentric data on the personal care network. To ensure that individuals' different reading levels and writing skills could be appropriately recognised, wording of both the questions and their answers (in case of closed-ended questions) needed careful consideration (Polit and Beck, 2010).

Based on the literature and the research question for the second phase (see section 2.4.3), an initial draft of the questionnaire was developed. Questions needed to prompt participants to elicit information on 'who' they had contact with in relation to their care by relying on their memory. At the same time, answers had to be comparable (Polit and Beck, 2010) and facilitate SNA. This resulted in the majority of the questions being closed-ended, requiring the participant to choose between pre-specified answer options. As all three areas of organisational contact (health, social and informal care) were to be included, pre-specified answer options drawn from the literature were developed to capture the most 'common' or likely answers. The answer options relating to health and social care providers were based on the list used by Personal Social Services Research Unit in their 2010 report on *'Unit Costs of Health and Social Care'* (Curtis, 2010). The options relating to informal care were based on studies in the scoping review that included (types of) social support (see section 3.2.2.3). Alongside information on the network, demographic data were collected including age, sex and, ethnicity. Data on ethnicity were collected by using the final recommendations as published in the white paper *'Help shape tomorrow'* for the Census 2011 (Cabinet Office, 2008). Participants were also asked to indicate the number and type of LTC they

were diagnosed with. A list of potential chronic LTCs guided the answer options and was based on the *'Long term health conditions 2011'* report carried out by Ipsos MORI (2011) for the DoH.

The initial draft of the questionnaire was reviewed by six members of the Healthier Ageing Patient and Public Involvement group at the University of Lincoln. Based on their feedback, an adjusted version was sent out for pilot testing among three members of the public (acquaintances that met the inclusion criteria for the study), two members of the East Midlands Later Life forum and two academics independent from and unfamiliar with the research. This group of people completed the questionnaire and provided feedback that led to the final necessary adjustments. The pilot test determined whether the questionnaire was useful in generating the desired information and if there were any caveats in the question logic (e.g. automatically redirecting people to the correct next question). The reason for this review process was twofold. Firstly, the construction of closed-ended questions is known to be more difficult than open-ended questions (Polit and Beck, 2010). Having these groups reviewing the questionnaire increased the likelihood that questions and their answer options were understandable, readable and feasible. Secondly, these reviews were put in place to reduce the possibility of overlooking potential common or important answers that were not included in the predefined answer options.

The final questionnaire (Appendix 4) existed of two main parts. The first section asked participants about the care and support they received, both formal and informal. The second section elicited demographic and LTCs information. To reach as many participants as possible, the questionnaire was provided both online and on paper (Evans and Mathur, 2005). As the dissemination of the questionnaire followed a similar process to the strategies used for raising awareness of the interviews, section 2.6.2 elaborates on the procedures for both methods.

2.6.1.2 Qualitative PCN data: semi-structured interviews

Interviews have been widely used as a data collection method in qualitative research. In this MMR study, it was decided to use semi-structured interviews in combination with questionnaires. The interviews were designed to be conducted face-to-face, but if preferred by the participant, telephone interviews would be undertaken. See section 2.5.2.2 for the reasoning behind these decisions.

Topic guide construction

The questionnaire did not intend to provide nuanced data on, for example, the 'strength' of connections that patients had with care providers. To address this, it was necessary to carry out a set of interviews. In order to address the overall rationale of this thesis (the study of the feasibility and acceptability of ICT to support older people with multimorbidity in their navigation through the care system), the second and third objective of the study (see section 2.4.3), the interviews needed to be responsive to participants, their individual experiences and context (Arthur and Nazroo, 2003), whilst ensuring that those issues needing to be addressed were incorporated. Thus, semi-structured interviews were deemed appropriate. Reflecting the research questions, findings and gaps highlighted by the literature review (Chapter Three), a set of questions was identified and formed the focus of the interview topic guide.

Arthur and Nazroo (2003) comprehensively discussed the purpose and nature of topic guides as well as providing guidance on creating and structuring useful guides. Following their guidance, an initial version of the topic guide was created. The topic guide was based on the objectives the semi-structured interviews wanted to contribute to (i.e. objective two and three, see section 2.4.3) and the patient-centred design framework. To assess if a digital navigation tool could be developed alongside users, supporting achievement of their goals and personalised care, a number of questions were essential. Any interview needed to

emerge patients' perception of the feasibility of such a support tool as well as their current experiences of, and barriers to, effective navigation through the health and care system. The final topic guide can be found in Appendix 5.

Before the first interview was carried out, a 'pilot' interview was held with a member of the public to gain insight into the 'flow' of the guide. This did not lead to any changes and the same topic guide was used during the first interview with a member of the target population. Based on the data gathered during this interview, no changes were found necessary to the topic guide (Appendix 5). After each interview, revisions continued to be undertaken, ensuring the data and subjects that needed to be covered were explored.

2.6.2 Sample size and criteria

Unlike conventional research methods, where appropriate sample size for a study is calculated based on confidence intervals or (relative) standard error; sample size and power calculations are uncommon in SNA. In addition, no listing existed of those living in the community with two or more LTCs. Therefore, no sample calculations could be made in the traditional way.

Although a purposive sample was drawn from the population, it was decided that between 50 and 100 completed questionnaires were needed for meaningful exploration. Obtaining less than 50 completed questionnaires would undermine the usefulness of descriptive analysis and endanger the possibility of exploring subpopulations in the data. Based on the SNA capacity, the cut-off point was set at a maximum of 100 completed questionnaires and 50 semi-structured interviews; resulting in an absolute maximal total sample size of 150.

Any individual who met the inclusion criteria, i.e 55 years or older, two or more LTCs and living in England, was invited to complete the questionnaire. Although it was emphasised that all those who met these criteria could participate, it was

recognised that those with cognitive impairments (e.g. moderate or severe dementia), might not have been able to recall service use data or complete the questionnaire. In a similar vein, it was acknowledged that individuals with communication or literacy problems, including limited English comprehension, might be unable to read and respond. The same inclusion criteria (55 years or older and two or more long-term health conditions) were applied to the interviews. However, in addition, participants also needed to live in Lincolnshire.

2.6.2.1 Setting and recruitment

The specifics of the sampling strategy differed slightly for the quantitative and qualitative strand. Three different approaches were used to raise awareness about the existence of the questionnaire. The material (including the final questionnaire) used for this can be found in Appendix 4.

A) Recruitment through the community

The link to the online version of the questionnaire was distributed via social media; the University of Lincoln's communication channels (e.g. Advertising of the study via University wide emails and twitter accounts) and specific third sector (voluntary and private) organisations (e.g. Age UK). Social media involved calls for participants via Facebook groups (e.g. hobby groups for older people, charity care organisations) and twitter feeds. Flyers were created and distributed in order to raise the visibility of the project, and to advertise the various ways people could participate in the study (i.e. online or via paper questionnaire). Flyers were, with agreement, placed in churches, community halls and charity shops. As such, potential participants that accessed the online link and/or requested a paper copy of the questionnaire were self-selected.

B) Recruitment through Lincolnshire GP practices

An additional recruitment strategy was employed in Lincolnshire. To ensure that participants who would also be eligible for the interviews (i.e. live in Lincolnshire) were found, 101 GP practices in Lincolnshire served as 'Patient Information Centres' (PIC's). None of the practices were asked to actively recruit patients, nor to provide any specific information or assistance. PIC's were solely used to display the poster they received from the researcher. This poster included a brief summary of the project, the link to the questionnaire and contact details to request a hardcopy of the questionnaire. These details were provided in a 'take-away' format and displayed in 37 practices in West Lincolnshire, 30 in East Lincolnshire, 19 practices in South West Lincolnshire and 15 practices in South Lincolnshire.

C) Recruitment through third sector organisation

In spring 2015, Age UK Lincoln implemented a funded Primary Care Navigator project. Patients were referred to the Primary Care Navigators from General Practices within the Lincolnshire West CCG Localities. In collaboration with Age UK Lincoln, these patients were approached to participate in the study. The Primary Care Navigators, as part of their normal contact with the patient, raised awareness about the study and provided the study pack (i.e. a paper version of the questionnaire, participant information sheet, informed consent and prepaid return envelope). Patients themselves decided whether or not they wanted to participate. If they did, they could choose to opt-in through completing the online questionnaire or the paper hardcopy. In case of the latter, they were asked to return both the informed consent and the completed questionnaire in the study pack through the prepaid envelope provided.

To increase the understanding of the day-to-day complexity of care navigation, on two separate occasions, different primary care navigators of Age UK Lincoln were joined during their visits.

2.6.2.2 Procedures

A) Questionnaire participation

Participants that visited the link to the online questionnaire were first presented with a front page describing the study in lay language and providing the option to request a hard copy of the questionnaire. The front page also informed patients about their entitlement to withdraw from the study at any time (without the need to explain). Contact details of both the researcher and an independent party were given in case they had any questions or wished to withdraw. People who decided to proceed to the next page were presented with more detail on the study and reiteration of the opportunity to withdrawal. This second page included the informed consent procedure and participants were asked to select one of the following options: *"I would like to participate and continue to the online questionnaire; I would like to participate and receive a paper-based version of the questionnaire; I would like more information before taking a decision; I would rather not take part"*. After selecting the second or third option, participants were directed to a contact form. This enabled the participant to either contact the researcher or to leave their contact details so they could be approached by the researcher. Only when selecting the first option, and thus providing consent, were participants able to fill out the questionnaire.

Participants completing the questionnaire on paper received the same information in a study pack (participant information sheet, informed consent and questionnaire) that also enclosed a prepaid return envelope. The responses from the paper based questionnaires were entered into the computer through the existing online link (i.e. the link used by participants completing the questionnaire

online). This assured that all data were stored in one overarching tool that then allowed extraction into Excel and CSV format. Questionnaire responses were accepted until June 2016, which resulted in a data collection period of six months. During this period, responses were screened to identify eligible participants for the interviews. Upon completion of the data collection period, the full set of responses was extracted into Excel to allow formatting and preparation of the data to be used in SPSS (IBM Corp) and Gephi (Mathieu et al., 2009).

B) Interview participation

Once the questionnaire was completed, eligible respondents (i.e. those living in Lincolnshire) were offered the option to express an interest in participating further through a semi-structured interview. Those who decided to do so, were asked to leave their contact details and preferred method of contact. Upon receipt of these, participants were contacted to further discuss the study, check their consent, and clarify any further questions the participant might have and arrange a date and time for the interview. In agreement with the participant, a place for the semi-structured interview was decided (usually the participant's home). Twenty-four hours prior to the interview, participants were contacted to check whether they were still willing to be involved and to address any points of query or concerns.

Before the interview was conducted, the consent form was explained and permission was sought to audio record the interview. Both the researcher and the participant were to sign the informed consent and both retained a copy. The audio files were transcribed verbatim and transcriptions did not include any identifiable information such as names. Audio files were password protected and stored securely according to the University of Lincoln's Research Data Management policy.

C) Ethical Approval

This doctoral study and the instruments used for data collection received ethical approval from the University of Lincoln's school of Health and Social Care and the NHS Research Ethics Committee (reference number 15/NI/0263). Two main pathways for data collection existed: online and paper based questionnaire (1) and semi-structured interviews (2).

C) Data analysis process

As described above, all questionnaire data were kept together on the online tool. The data were extracted into Excel in which responses were cleaned, coded (i.e. narrative responses were coded) and followed up (i.e. people volunteering for an interview were contacted). After cleaning, the Excel file was exported into SPSS for the conduction of descriptive statistics. Data were further explored for differences between groups (e.g. younger and older people in the sample), however when analysing on this level (e.g. t-tests), numbers became small and thus interpretation of the results in Chapter Four needs to bear this in mind.

In addition to the descriptive statistics via SPSS, the database was uploaded into Gephi which allowed for visualisation of the data in accordance with social network principles. Alongside this overall database in Gephi, the data from the questionnaire respondents that also participated in the interviews were uploaded into separate Gephi databases to allow for individual SNA exploration before the interview. These individual visualisations (maps) of the PCN were taken to the interviews and shown to the participant.

The anonymised interview transcripts were line-by-line coded and further analysed using a framework for analysis (see section 4.2.2). Initial open codes were grouped into categories which were then allocated to the themes in the framework. Special attention was given to those data that helped to address the

research questions and elements that supported one of the six components of the underpinning Patient-Centred Design framework.

2.7 Conclusion

The aim of this thesis was to fill gaps in knowledge with regard to PCNs and care navigation in the setting of multimorbidity, and to provide suggestions on how to improve care navigation and deliver design requirements for the development of digital care navigation support.

This chapter presented the different options, in terms of paradigms and methodology that underpinned this study. A variety of research questions were put forward to be answered in this thesis. The nature of these questions required the need for various types of data and different analyses. This determined the decision to use a pragmatic research paradigm, a research paradigm that prescribed the use of the most appropriate and useful method(s) to address the research questions.

In addition, the reader was given an overview of the study design, including the three phases comprising the study. The methods used in each phase were briefly outlined with cross-references to the according chapters for more detail. Each phase further aligned with the objectives set for the study as shown in Table 5.

Table 5: Aims and objectives, research questions and methods of the study

AIMS AND OBJECTIVES	RESEARCH QUESTIONS	METHOD	FINDINGS
Synthesise the literature on care navigation among older people with multimorbidity from a patient perspective.	What does the literature regarding care network/system navigation in the setting of older people with multiple morbidities tell us?	Scoping Review	Chapter Three
Analyse and visualise the structures of and interactions in the personal care network (PCN) of older people with multimorbidity and gain an understanding of their experiences of navigating their PCNs.	What does the care network of older people with multimorbidity look like from a patients' perspective? a) Which actors are involved in the PCN of older people with multimorbidity and from which care domain (social care in the community, health care in the community, health care in the hospital and informal care)? b) Does this structure of the PCN differ according to the number of LTCs, age and sex?	Egocentric Social Network Analysis (SNA) of questionnaire data	Chapter Four

	c) Why are these actors present in the PCN of older people with multimorbidity? d) Does this reason for involvement differ according to the number of LTCs, age and sex? e) How are actors involved in the PCN of older people with multimorbidity?		
Identify elements for improvement in care navigation among older people with multimorbidity and deliver design requirements for the development of an ICT tool to support this population in their navigation through the care network.	How does the care network of older people with multimorbidity function in the opinion of the patients? How can ICT support patients in the tasks of navigating and interacting in their care network?	Egocentric SNA of questionnaire data Framework Analysis of interview data Data-driven, evidence-based personas	Chapter Five

3

Literature Scoping Review

This chapter reports on the process of the literature synthesis conducted to answer the research question 'What does the literature tell us regarding care navigation in older people with multimorbidity?' The four steps described by Arksey and O'Malley (2005) for conducting scoping reviews are detailed, involving: the identification of relevant studies (section 3.1.1.), the selection of relevant studies (section 3.1.2), charting the data of selected literature (section 3.1.3) and collating, summarising (section 3.1.4) and reporting the results of the scoping review (section 3.2). In addition, insights into the use of the scoping review results for this particular study (section 3.3) are provided. In this final section, the scoping review results are placed in their wider context.

3.1 Process of the systematic scoping review

3.1.1 Identification of relevant studies

To locate studies relevant to the research question, different approaches were used. Five academic databases and ten grey literature sources were selected (Table 6). These sources were discussed with and reviewed by a subject librarian to ensure all prominent options for the scope of this research were included.

Table 6: Scoping review databases and sources

NAME OF SOURCE	TYPE OF SOURCE
CINAHL	Electronic database
MEDLINE	Electronic database
SCIENCE DIRECT	Electronic database
ACM DIGITAL LIBRARY	Electronic database
IEEE	Electronic database
THE HEALTH FOUNDATION	Grey literature
UNIVERSITY OF LINCOLN SEARCH DATABASE	Grey literature
GREYLIT	Grey literature
THE KING'S FUND	Grey literature
SOCIAL CARE INSTITUTE FOR EXCELLENCE (SCIE)	Grey literature
OPENGREY	Grey literature
NATIONAL TECHNICAL INFORMATION SERVICE (NTIS)	Grey literature
ETHOS	Grey literature
INDEX TO THESIS	Grey literature
HEALTH MANAGEMENT INFORMATION CONSORTIUM (HMIC)	Grey literature

In the first instance, trial searches and combinations of the key terms were created for each database. These were carried out to define those search strings that would yield the most relevant results without losing valuable information. The final key terms and different search strings can be found in Table 7.

Table 7: Search terms and combinations for scoping review

SEARCH STRING
Navigat* AND multi*morbid*
Navigat* AND complex care settings
Navigat* AND (multi*morbid* OR long term* OR chronic*)
“care navigat*” AND (multi*morbid* OR long term* OR chronic*)
“care navigat*” AND (multi*morbid* OR long term* OR chronic*) NOT (space OR catheter OR care)
(navigat* OR "navigat* model" OR "pivot nurse" OR wayfinder) AND (multi* morb* OR "complex care setting" OR chronic* OR long term*)
(navigat* OR "navigat* model" OR "pivot nurse" OR wayfinder) AND (multi* morb* OR "complex care setting" OR chronic* OR long term*) AND age* OR elder* OR older*
(navigat* OR "navigat* model" OR "pivot nurse" OR wayfinder) AND (multi* morb* OR "complex care setting" OR chronic* OR long term*) AND age* OR elder* OR older* (NOT space)
Elder* OR older* AND “care navigat*”
Elder* OR older* AND “care navigat*” NOT space NOT catheter NOT car NOT robot
Navigat* AND “patient journey”
Navigat* AND (long term* OR chronic* OR mult* morbid*)
Navigat* AND (long term* OR chronic* OR mult* morbid*) NOT space NOT car NOT catheter
(Care AND navigat*)
(Care AND navigat*) NOT space NOT car NOT catheter

Whilst it was recognised that the literature around care navigation in single LTCs could potentially provide relevant information for this study, it was decided to focus solely on multimorbidity. Previous literature has indicated the importance of looking at multimorbidity as a unique setting (see Chapter One) and this study

was particularly interested in the 'tension' that managing multiple LTCs could bring to different care providers and thus navigation challenges. Nevertheless, as shown in Table 7, the search terms 'long term' and 'chronic' were used to ensure inclusion of those relevant papers that did not necessarily use 'multimorbidity' in their key terms.

3.1.2 Selection of relevant studies

Priority in the scoping review was given to developing a broad overview, rather than an in-depth appraisal of the quality of the literature as such. This resulted in defining limited inclusion criteria at the start of the literature searches. Papers had to be published between 2003-2014 and be written in English, French, Dutch or German. This time span was chosen after initial exploration of the search results across databases. Paniagua (2002) suggests a timespan of five to ten years for literature reviews (excluding seminal or influential work). On the one hand the scoping review had to provide a broad coverage of the literature, on the other hand the publications needed to be relevant both in terms of the topic and societal context. The decision on languages was primarily guided by time and budget constraints. Often, significant academic contributions are published in English. The other three languages would not require translation by a third party (i.e. I was able to process these myself) and thus were added to the search.

Whilst the use of minimal inclusion criteria could result in the identification of papers (based on their title and abstract) that would later be excluded; this inclusive stance ensured that the likelihood of missing potential relevant papers was reduced. However, it needs to be pointed out that potentially relevant papers could still have been omitted due to the timeframe and language restrictions set in the search. To manage the potential large number of papers retrieved from the searches, a systematic selection process was carried out, starting with title and abstract reading (see Figure 11). Selected articles were then subject to a second

round of detailed abstract reading combined with in-depth full text reading. The outcome of this phase determined the final decision of inclusion or exclusion of the paper. Finally, information was collected from the selected papers using an analytic framework for data extraction (Appendix 6).

A total of 3171 papers was initially identified (see Figure 11). Title and abstract reading led to the extraction of 367 studies in relation to older people with chronic conditions and navigating the care system. Selected studies were then subject to more in-depth abstract and full text reading, which resulted in the exclusion of a further 128 papers (e.g. papers that solely focussed on cancer care, papers that discussed the health care insurance side of LTCs).

The remaining 239 papers were organised according to their relevance. This was judged based on: population (e.g. older people, multimorbidity or single chronic condition) and topic of study (e.g. navigation, case management, management of chronic conditions). On closer inspection, almost half (114) of the papers related to navigating the care system, but did not focus on older people with multimorbidity as a population; a far smaller amount of papers (14) related to a different activity than navigation (e.g. communication platforms, adaptive patient journey record systems), albeit focused on the population of older people with multimorbidity; 37 other papers retrieved were regarding best practice and 44 on technical issues around navigation. Ultimately, 46 papers were perceived to relate to the main issue of care navigation by older people with LTCs. A flowchart of the selection process is given in Figure 11.

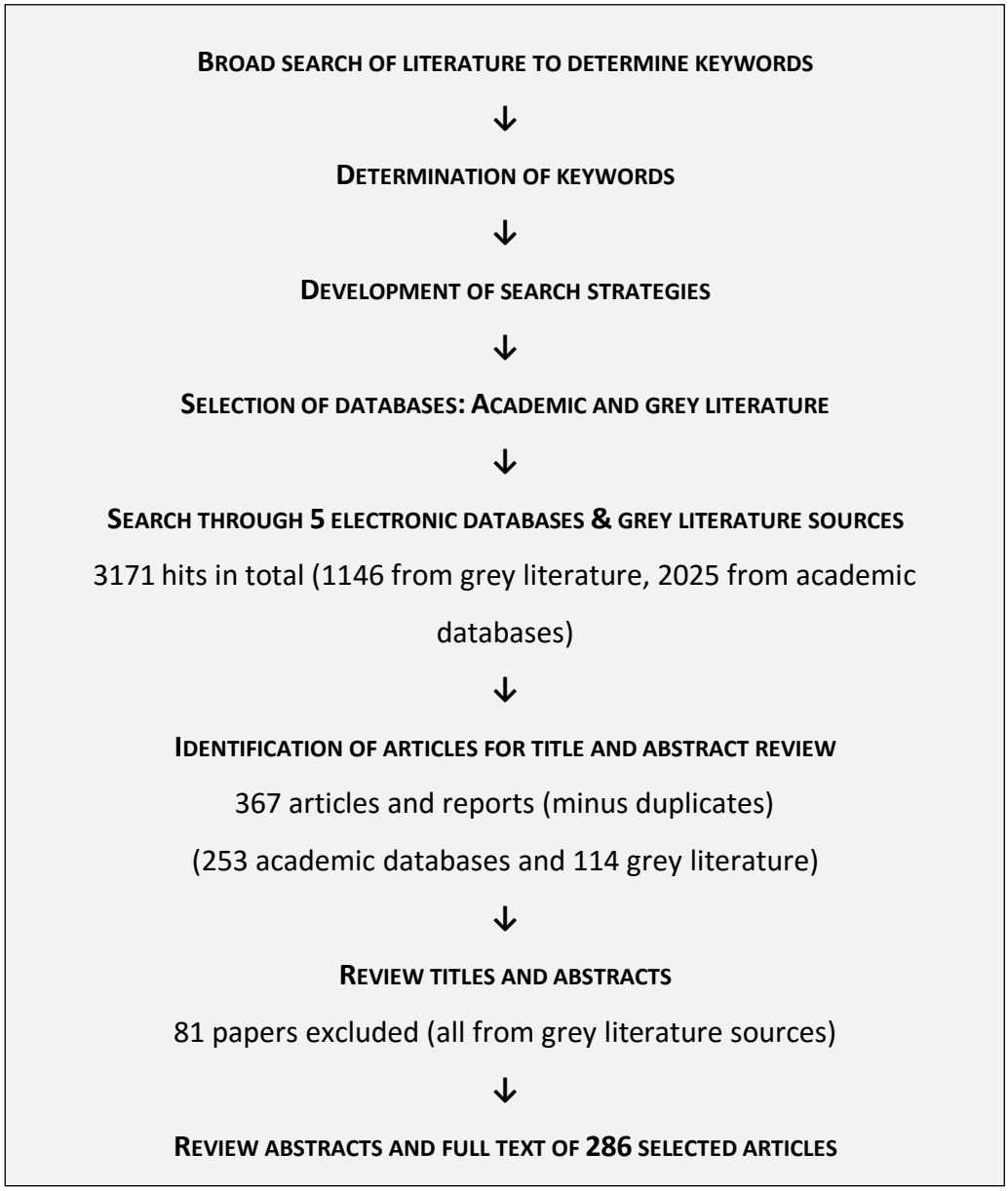


Figure 11: Flowchart of selection of scoping review literature

3.1.3 Charting the data

Analysis and data charting was conducted for the full texts of the final 46 papers. A charting framework, (Appendix 6), assured systematic collection of the same type of data across the papers. Information on the authors, publication year and journal, type of literature, title, population, study location, aim, study design,

sample characteristics and important findings was systematically collected for all papers. This detailed data extraction method and an increased familiarity with the literature resulted in a further system of 'grouping' the 46 papers. Through the use of the PICO (Population, Intervention, Comparison, Outcomes) concept, these 46 papers were divided and categorised according to relevance to the study:

- Population: older people (55 years or older) with multimorbidity or LTC.
- Intervention: care navigation, case manager, care coordinator or integrated care model.
- Comparison: previous care, care in absence of care navigator programme.
- Outcomes: effect of care navigation support in terms of patient outcomes (e.g. wellbeing, satisfaction, experiences).

In total, 15 papers were marked as important context papers (relating to none or only one aspect of the PICO) and 19 papers were perceived to be less relevant (relating to one or two broad elements in the PICO). A further 12 final papers were perceived as helping to gain a better understanding of navigation through the care system by older adults and/or described possibilities to support this (Table 8). Three or more elements of these final papers related to the PICO, unless it concerned an 'issue brief'. In case of the latter, they would be included in the final selection if they were found to provide additional information on the topic of care navigation in older people with multimorbidity.

Table 8: Selected papers in the scoping review

REFERENCE	AIM OF STUDY	PICO	EMERGED THEME(S)
Advancing Knowledge of Telecare for Independence and Vitality in Later Life [AKTIVE] Consortium (2013). The role of telecare in meeting the care needs of older people: Themes, debates and perspectives in the literature on ageing and technology. *AKTIVE research report Vol.1*	Describing possibilities of technology	N/A	Issues and needs expressed
Albert, B. (2012). Navigating care management. *Healthcare Financial Management,* 66(12), 62-66.	Describing the concept of care navigation	N/A (Issue brief)	Care navigation as a response Outcomes of care navigation
Bhandari and Snowdon (2012). Design of a patient-centric, service-oriented health care navigation system for a local health integration network. *Behaviour & Information Technology,* 31(3), 275-285.	Descriptive study: describing the design of support tool	✓ Intervention ✓ Comparison ✓ Outcomes	Issues and needs expressed Outcomes of care navigation
Brossoie et al. (2010). Report on baby boomers and older adults: information and service needs. *Virginia Polytechnic Institute and State University, Center for Gerontology.*	Gaining understanding	✓ Population ✓ Comparison ✓ Outcomes	Issues and needs expressed

REFERENCE	AIM OF STUDY	PICO	EMERGED THEME(S)
Ferrante et al. (2010). Translating the Patient Navigator Approach to Meet the Needs of Primary Care. *Journal of the American Board of Family Medicine,* 23(6), 736-744.	Explorative study: gaining understanding of experiences of a patient navigator process	✓ Population ✓ Intervention ✓ Comparison ✓ Outcomes	Care navigation as a response Outcomes of care navigation
Jackson et al. (2012). Patient Journey: Implications for Improving and Integrating Care for Older Adults with Chronic Obstructive Pulmonary Disease. *Canadian Journal of Aging,* 31(2), 223-233.	Explorative study: gain understanding of patient journey (up until three months after discharge)	✓ Population ✓ Intervention ✓ Outcomes	Issues and needs expressed
Manderson et al. (2012). Navigation roles support chronically ill older adults through healthcare transitions: a systematic review of the literature. *Health & Social Care in the Community,* 20(2), 113-127.	Systematic Review: gaining understanding through existing literature and models for support	✓ Population ✓ Intervention ✓ Comparison ✓ Outcomes	Care navigation as a response Outcomes of care navigation
Ramalingam, S. (2010). Navigating health care. *Smart business Pittsburgh.*	Gaining understanding	N/A (Issue brief)	Care navigation as a response
Ravenscroft (2010). Navigating the health care system: insights from consumers with multi-morbidity. *Journal of Nursing & Healthcare of Chronic Illnesses*, 2(3), 215-224.	Explorative study: gaining understanding through interviews	✓ Population ✓ Intervention ✓ Comparison ✓ Outcomes	Issues and needs expressed

REFERENCE	AIM OF STUDY	PICO	EMERGED THEME(S)
Ravenscroft (2006). A patient perspective on health care system navigation in the context of multi-morbidity: Implications for health care systems redesign. *The CANNT Journal: conference abstract*, 16(3), 21-22.	Conference abstract relating to article Ravenscroft (2010)	✓ Population ✓ Intervention ✓ Comparison ✓ Outcomes	Issues and needs expressed
Rein A. (2007). Navigation Health Care: Why It's So Hard and What Can Be Done to Make It Easier for the Average Consumer	Describing the issues relating to care navigation	N/A (Issue brief)	Issues and needs expressed
Yao et al. (2012). A Context-Aware Framework for Patient Navigation and Engagement (CANE). *In 8th International Conference on Collaborative Computing.*	Descriptive study: describing support tool	✓ Population ✓ Intervention ✓ Comparison	Need for information and advice Care Navigation as a response

3.1.4 Collating, summarising and reporting results

The systematic process of data charting described above, resulted in the identification of reoccurring findings that were clustered as themes. The results of the scoping review are discussed in the section below, reporting the expressed needs and issues emerging from the literature (sections 3.2.1 and 3.2.2 respectively) e.g. the type of information and advice patients require, how care navigators might be a response to this (section 3.2.3), the available care navigation programmes in this context and their outcomes. Section 3.3 goes beyond the scoping review, placing results into context and forming the foundations for the rest of this doctoral study.

3.2 Results of the scoping review

Care delivery to people with more than one chronic condition is a major challenge and opportunity in today's care landscape. As multimorbidity is becoming the norm rather than the exception (Fortin et al., 2007:1016), gaining insight into care systems and delivery is increasingly important to support system redesign, problem identification and improvement of the quality of care (Bhandari and Snowdon, 2012; Ravenscroft, 2010). It should be noted that the majority of the literature was drawn from the USA. Although this might not affect the practical issues surrounding navigation (Albert, 2012), it would be likely to have an impact on the financial context (e.g. funding care navigator programmes).

3.2.1 Issues in navigating the care system

As discussed in Chapter One, the health care system was not designed with multimorbidity in mind. It was initially designed for single diseases and acute events (Ravenscroft, 2010). As a result, little was known about how two or more

major chronic conditions intersect and interact, and particularly on how this affected the patient journey through the health care system (Ravenscroft, 2010). **Patient navigation**, as a concept, emerged as a way of characterising the experiences of consumers in health care and comprised

> *"the process(es) by which patients and/or their health caregivers move into and through the multiple parts of the health care enterprise in order to gain access to and use its services in a manner that maximizes the likelihood of gaining the positive health outcomes available through those services" (Rein, 2007:2).*

The process of care navigation is challenging in our current systems, particularly for those who are sick and distressed (Ramalingam, 2010; Ravenscroft, 2010). Two main themes arose from the study of Ravenscroft (2010): navigating the health care system was, according to patients with multimorbidity, *'navigating rough terrain'* and *'discovering how to manage the system'* (Ravenscroft, 2010:215).

Locating the right services at the right time was a *'difficult'* task for the public owing to *'the absence of a system-level navigation tool'* (Bhandari and Snowdon, 2012:275). Jackson et al. (2012:228) further reported that system navigation was described by patients as *'complex and, at times, frustrating'*. Experiencing fragmented and disjointed health care delivery (Ramalingam, 2010), together with difficulties in access and lack of access to adequate information, led to frustration (Ravenscroft, 2010). What may be perceived as 'minor' frustrations by physicians were rather more burdensome obstacles for patients who were necessarily navigating the health care system (Ravenscroft, 2010).

As *'the health care system becomes more complex, it also makes consumer engagement even harder'* (Yao et al., 2012:316). Alongside the disjuncture and misalignments in the health care delivery system (Ramalingam, 2010; Ravenscroft, 2010), the possible cumulative health care related burden of multimorbidity for

consumers (Ravenscroft, 2010) required further work in *'how patients currently deal with system complexity'* (Rein, 2007:3). The latter was perceived as one of the research priorities in this area by Rein (2007).

Jackson et al. (2012) mainly explored the experience of patients with a single LTC (COPD), mapping these patient's journeys during the three months after discharge from the hospital. This provided insight into the high number of providers involved. Patients were required to attend a myriad of encounters to manage their health and care needs; specialised health care services were accessed in various locations over extended periods of time together with receiving visits from home care and/or appointments in general practice. Jackson et al. (2012) further pointed out that the scheduling of these encounters could add to patients' frustration (e.g. five appointments in one week whilst no appointments the next week). According to the findings of Ravenscroft (2010), a magnifying effect of these frustrations was seen amongst patients with multimorbidity. This was reported to be the result of patients repeatedly encountering similar 'obstacles' as they had multiple LTCs which increased their frustration (Ravenscroft 2010). Examples of obstacles mentioned by Ravenscroft (2010) included: problems relating to what and how information is shared with patients, contradictory information and logistical issues such as parking and transport.

Along with expressing these more practical issues, patients reported that navigating the health care system was a process of on-going discovery, particularly with regard to *'the social structures within which their health care was delivered'* (Ravenscroft, 2010:220). Patients were reported as learning from their experience. Whilst moving through the system, they discovered the different parts it comprised, and that these often operated as separate entities (Ravenscroft, 2010). Different parts did not work together, nor were they connected in ways that patients assumed (Ibid). In addition, patients learned that providers were

difficult to differentiate by profession or position and varied in competence and knowledge (Ravenscroft, 2010).

Patients felt that there were unspoken expectations and preferences with regard to how they should interact with and access the health care system. Their interactions with different parts of the system were regulated by unwritten rules. For example, findings of Ravenscroft (2010:220) revealed that *'A lot of doctors won't answer your questions over the phone. They want you to make an appointment'* and *'You can get things done more efficiently if you sort of follow the rules'*. Through trial and error, patients learned about the health care context only as part of any encounter. It was through their experience that patients with multimorbidity discovered that what they considered to be reasonable expectations of health care services were often unrealistic (Ravenscroft, 2010). However, no examples were provided as to what those unrealistic expectations were. Ravenscroft (2010:220) also reported that *'how the care system was set up required a great deal of luck to negotiate successfully'*. Previous experiences influenced these expectations and an increase in satisfaction was mentioned when those expectations were met (Jackson et al., 2012). Prior experience also played an important role in helping patients to find their way through the system (Jackson et al., 2012). It allowed them to anticipate which services might be available and improved their understanding of each organisation's structures and processes and what support may or may not be available around their health and social care needs (Jackson et al., 2012).

3.2.2 Patients' needs in navigating the care system

Based on cues and through prior experiential learning, patients reported that they *'tactically work around or improve health care situations by using their knowledge to improve care coordination'* (Ravenscroft, 2010:221) albeit often on the basis of trial and error. By actively advocating for themselves; being strategic about

approaches to interpersonal relationships and using these to improve care and access to care, services and providers, patients learned to find ways to manage their situation (Ravenscroft, 2010). It was about taking advantage of the people they knew in order to find those 'loopholes' in the system that they could then jump through (Ravenscroft, 2010). Even with these active efforts to bridge the gaps as they navigated through the system (Ravenscroft, 2010), a lack of knowledge often resulted in their expectations remaining unmet (Jackson et al., 2012).

3.2.2.1 Need for practical support

The lack of a roadmap, direction or guidance on which service (or intervention) to access and when this should be used, emerged from the literature. This made navigating the care system a challenging and burdensome task for patients (Bhandari and Snowdon, 2012; Ravenscroft, 2010). Over half of the respondents in the study of Brossoie et al. (2010) stated that in any future activity, they would seek assistance in coordinating and obtaining appropriate services (i.e. navigating). Respondents expected to need help with coordinating services, assessment of service needs, coping with LTCs and issues faced in later in life. These views were highly prevalent in those aged 45-64 years (Brossoie et al., 2010). The older-old (85 years and over) were significantly less likely to state that they would use (or need) specific support with identifying appropriate care provision than any other age group. Brossoie et al. (2012) suggested that, at this stage, they might have already identified those services they needed to continue to remain independent in their own homes. The importance of this aspect of prior experiential learning was also highlighted by Ravenscroft (2010) and Jackson et al. (2012).

The need for practical support derived from clear evidence that users experienced their care as fragmented (Ravenscroft, 2010). This was particularly the case when

patients had more than one LTC, reporting a magnifying effect of discontinuity in care, inadequate support for self-management and logistical issues (Ravenscroft, 2010). Helping patients to manage their health care by providing them with a unified and integrated view of their specific care continuum (bringing all pathways and providers together in one flow chart), was the main foundation for the CANE project by Yao et al. (2012).

Kodner (2008) conceptualised integrated care as *'designed to create coherence and synergy between various parts of the care enterprise, in order to enhance system efficiency, quality of care, quality of life and consumer satisfaction, especially for complex and multi-problem patients or clients'* (Jackson et al., 2012:224). It was this lack of integrated and well-coordinated care that added to patients need for practical support (Jackson et al., 2012; Ravenscroft, 2010).

3.2.2.2 Need for informational support

To successfully navigate the fragmented systems in place on the ground, adequate information was essential. Difficulties in obtaining *'appropriate and sufficient information from providers'* were mentioned in the study by Jackson et al. (2012:229). Patients' concerns did not seem to be discussed as much as they wanted and some felt that their provider did *'not say anything'* and they had *'to ask for information'* themselves (Jackson et al., 2012:229). Whilst the latter, (asking questions), was not necessarily perceived as problematic by all patients, it was seen as a problem if patients felt a *'lack of opportunity to ask questions'* or were unaware of *'what they should ask providers in order to help better manage their condition'* (Jackson et al., 2012:229). Uncertainty about the 'right' questions as well as a frequent lack of opportunities to ask questions and problems in open information exchange again resulted in unmet needs (Jackson et al., 2012).

Good interpersonal skills between patient and clinician/professional were mentioned as an important element in any encounter. This also influenced the

quality of the patient-provider relationship, which in turn was associated with the ability to navigate the system (Jackson et al., 2012). Nevertheless, the need for good relationships and information exchange in the care context was not limited to patients and their providers. Effective provider-provider communication was of equal importance and patients were unsure if information was communicated to other providers. This vagueness often left them with the responsibility to, for example, update providers about changes in their treatment or remind them to send updates to other providers (Jackson et al., 2012). According to Bharandi and Snowdon (2012) this remained a frequent problem due to the majority of information systems still being internal to organisations. The systems did not allow connection or communication with external systems in other agencies or regional centres (e.g. Local Health Integration Networks [LHIN]). Therefore, seamless flows of information between different organisations seemed uncommon (Bharandi and Snowdon, 2012).

Brossoie et al. (2010) pointed out that baby boomers (45-64 years old in their study) and older adults (over 65 years old) had both common interests as well as distinct needs for information. As the ageing population represents such a wide range of individuals, service providers should identify their primary audience and recognise differences in their interests and need for information and how they are likely to access this information (Brossoie et al., 2010). Information on home and community based services as well as medicine in general, seemed to be the primary information needs reported by participants aged 65-74 years. Moreover, the ways in which people preferred to receive this information differed. Although printed materials and television were the most common, over 40% of people were likely to go on the internet, and approximately one third indicated that they would also seek information from electronic social media such as Facebook (36%), twitter (26%) and YouTube (32%) (Brossoie et al., 2010).

3.2.2.3 Need for social care support

Social support, especially following discharge from hospital, was reported to increase quality of life as well as *'the quality of interactions with the health care system'* (Jackson et al., 2012:226).

Social care support encompassed practical or physical (e.g. assistance with daily activities), emotional, instrumental (e.g. help with finances) and informational assistance. It was the latter (i.e. informational support) that emerged in Jackson et al.'s (2012) study as perceived to enable and enhance the interaction with the health care system. Some patients who had multiple encounters with providers especially benefitted from having someone with them during these visits. This additional person could, for example, help them understand and remember instructions, as well as advocate for the person (e.g. making sure his/her health needs were met) (Jackson et al., 2012).

Since patients tended to *'discover'* and *'learn'* how the system works through (current and past) experience (Ravenscroft, 2010:220), social support also brought more 'knowledge' (experiences of friends and family) to the picture (Jackson et al., 2012). Using collective experiences of family and friends, together with their own understanding, guided their journey (Jackson et al., 2012).

3.2.3 Care navigators as a response in the context of multimorbidity

These practical, informational and social care needs and issues, were considered to be the core activities and tasks of care navigators (Ferrante et al., 2010). Care navigators, care managers, patient navigators, etc., all referred to 'a person' concerned with the process of patient navigation. Although one of the tasks of care navigators involved 'social care needs and issues' (Ferrante et al., 2010), a strong health care perspective was noted in the description of patient navigation:

'The process of helping patients to effectively and efficiently use the health care system' (Ferrante et al., 2010:736).

Care navigators were reported to *'try to meet patients' needs and help them keep on track'* (Albert, 2012:62).

3.2.3.1 Available programmes: barriers and facilitators

Care navigators were successfully used in the cancer setting (Huber et al., 2014; Natale-Pereira et al., 2011; Willis et al., 2016) and recently within the setting of specific single diseases (e.g. COPD) (Ferrante et al., 2010) or, at particular moments on the care continuum (e.g. the transition between hospital and home) (Jackson et al., 2012). Studies pointed out that widening the use of care navigators in the care system would be beneficial in a society where both specialisation and (lack of) coordination are present (Ferrante et al., 2010; Rein, 2007).

Helping patients navigate the complex and fragmented USA health care system and coordinating their care were central to the 'patient-centred medical home'. The patient-centred medical home was a new model of care in the USA that *'aimed to reform the health care system into one that was more patient centred, accessible, effective, safer and efficient'* (Ferrante et al., 2010:736). Similar to the 'house of care' in the UK (see section 1.1.3), the 'medical home' was introduced in the USA with the aim of providing comprehensive and high quality primary care. It initiated a reorganisation in the way primary care practice was provided in the USA and as such strengthened the overarching health care system (Lipson et al., 2011).

One of the innovations in care navigation was to place care navigators in primary or community care provision. However, integrating this new role in group practices was found to be challenging, with costs and lack of onsite workspace as main barriers (Albert, 2012; Ferrante et al., 2010). Only in solo practices did patient

navigators feel part of the team. In their study looking at patient navigators in primary care, Ferrante et al. (2010:742) stated that *'although costs of adding staff or IT services are known barriers to achieving a patient-centred medical home, the costs of adding workspace is often underappreciated'*. However, their findings suggested that this onsite working space for in-person visits was an important factor in ensuring effective service coordination (Ferrante et al., 2010).

The value of a patient navigator might not have been evidenced at the level of the individual practice, but perhaps more at the wider health care system level (Ferrante et al., 2010). Despite reported benefits, the effort of changing the fundamental care delivery process to support the role of a care navigator was not without obstacles. Providers were often unwilling to fund such a role, despite the evidence of improved outcomes. However, according to Albert (2012), the need for care navigation would become evident in an environment of health care reform. Albert (2012) suggested five steps for the development of care navigation models in health care: determining areas of risk, identifying a target population, finding the right staff to support the model, outlining protocols and best practices, and expanding the scale of the programme. Once developed, these models could tackle some of the health care's deep-rooted problems such as preventable readmission or redundant and expensive tests (Albert, 2012).

Some studies explored ICT solutions to overcome the challenges to coordinated care or the barriers perceived with 'a person' fulfilling the care navigator role (AKTIVE consortium, 2013; Bhandari and Snowdon, 2012; Yao et al., 2012). Issues with communication and information exchange outside the organisation seemed to remain present, often due to technical restrictions on the flow of information (Bhandari and Snowdon, 2012). Personal health records could foster this exchange of information as they allow patients to store, view and share medical histories, medications, etc. (Yao et al., 2012). However, these did not help patients in making decisions towards a better understanding of their conditions, neither did they

facilitate the process of visiting multiple providers for different purposes (Yao et al., 2012). According to Yao et al. (2012) navigation programmes needed to truly focus on patients in order to help them to manage this task.

In their design of an ICT support tool for navigation, Bhandari and Snowdon (2012) highlighted the difficulty the public found in locating the right services at the right time. Their study looked in particular at LHIN in Canada. These LHIN were expected to plan, identify, integrate and fund health services and priority programmes for their regions. According to Bhandari and Snowdon (2012) system navigation was difficult due to the absence of a system-level navigation tool that gave an overview of the services provided by the LHIN.

Although it could be argued that system navigation is specific to the local health and social care environment (country specific), some problems, difficulties and barriers (e.g. a lack of accessible information on where to go) were considered likely to be seen in other areas (Albert, 2012). In order to help patients in this task of navigation, Bhandari and Snowdon (2012) discussed an on-going system design project of a patient-centred, service-oriented navigation system to be used by the public for accessing regional health care services funded by the LHIN in Canada. Thereby they questioned how the philosophy of service orientation could be applied in this tool and what the role of service design elements was on the user's acceptance and usage of technology (Bhandari and Snowdon, 2012). Bhandari and Snowdon (2012) explored how to close the gap, through technology, between the public and health care services available to the individual. They highlighted that a previous study had explored a system navigation programme, but this was not an automatic computer tool (Bertoni, 2009 in Bhandari and Snowdon, 2012). The ConnexOntario was another attempt in this direction, but was limited because it provided only basic information. For LHIN they wanted to develop service ontology for all the LHIN-funded member agencies. All health services available to the regional population served by the LHIN were reviewed to investigate the

services, the populations served, the access process for each service and the geographic distribution of the available services. Health services were further organised according to the main type of health needs of the population.

All of the provided services were organised into these categories of services and subcategories were identified to provide the necessary level of detail. Underlying service delivery concepts were identified and a prototypical system was developed and successfully validated (Bhandari and Snowdon, 2012).

3.2.3.2 Fulfilling the role of care navigator

The idea of using care navigators across the wider health and social care environment, generated a debate on which type of person, in terms of qualifications and training, should fulfil this position and in which settings this could be operationalised (Ferrante et al., 2010; Manderson et al., 2012).

The literature seemed to demonstrate that the types of roles of care navigators were dependent on their position and setting. Overall their roles varied from the provision of psychosocial support (e.g. hospital discharge planning) to coordinating and accessing services, including tasks such as making phone calls, meeting patients, updating physicians and providing information (Ferrante et al., 2010; Manderson et al., 2012). The 'patient-centred medical home' pointed out that patient navigator services involved the following tasks: making phone calls to patients or family members, meeting patients in person, updating physicians, contacting other physicians, researching and contacting community resources, phone or in-person assessment of patients, locating ancillary resources and arranging social services for elderly patients, providing the information and calling to actually arrange the appointments (Ferrante et al., 2010).

Patient navigator services tended to have many tasks related to start-up during the earlier months, collection of data from the patient and wind-down activities

during the later months (Ferrante et al., 2010). However, in all the activities mentioned, one overarching element was incorporated: the act of *'advocating for the patient and broker access to appropriate care'* (Manderson et al., 2012:122).

Typically, when care navigators were brought into cancer care, the tasks were undertaken by nurses with advanced training. Manderson et al. (2012:122) pointed out that the use of *'hands on clinical nursing duties'* was however uncommon, which opened a debate as to the type of qualifications necessary and exploring possibilities of e.g. using social workers. It was the latter who were employed in primary care in the study by Ferrante et al. (2010). For patients, the type of qualification did not seem to make much difference. However, primary care physicians in the study of Ferrante et al. (2010) reported that they would, in the future, prefer a nurse to fulfil the role of patient navigator. They stated that had a trained nurse undertaken this role, they would *'have probably referred different types of patients to the patient navigator and had her concentrate more on tracking specialist testing and following up patients'* (Ferrante et al., 2010:742). Manderson et al. (2012) focused on navigation roles outside of the cancer care setting, supporting chronically ill older adults through health care transitions. They concluded that most studies relied on nurses to fulfil these roles. The type of personnel (in terms of their qualifications and training) was found to affect the operationalisation of patient navigation, the type of patients who were assisted and the services provided (Ferrante et al., 2010).

3.2.3.3 Outcomes of care navigator programmes

The lack of clarity and directions on how to access services, resulted in *'patients often taking confusing and difficult paths or end up reaching the wrong destination'* (Bhandari and Snowdon, 2012:275). Besides inefficient use of the system, inaccurate access and going to the 'wrong place' at the 'wrong time',

patients also delayed access owing to a lack of knowledge or information as to what was the correct pathway (Albert, 2012; Bhandari and Snowdon, 2012).

At the patient level care navigation programmes were shown to be beneficial. They increased satisfaction, quality of life and functionality (Albert, 2012; Manderson et al., 2012). Patients with COPD and their family members reported that they *'gained information and services that they would not have received otherwise'* (Ferrante et al., 2010:741). They appreciated the availability of an individual who could work alongside them to provide information, support and guidance; all of which had a positive impact on the quality of life and their psychological wellbeing (Ferrante et al., 2010). They felt fortunate to have such support and even those who reported having a good support network said that although they did not personally need the service, they were positive about this intervention and thought it would be *'helpful for others'* (Ferrante et al., 2010:741). Emotional support for patients and family members also enhanced communication between physicians and patients (Ferrante et al., 2010; Jackson et al., 2012).

At the level of care providers, it was reported that physicians did not perceive the patient navigator as filling an existing role in the practice, but rather, they carried out tasks that the practice had not previously undertaken (i.e., helping patients to find the needed resources and coordinating care beyond referral administration). Some physicians praised the use of patient navigators. However, others thought *'it would be more useful if patient navigators focused on identifying and intervening with patients who were receiving fragmented care and on fostering population-based care'* (Ferrante et al., 2010:741). These were elements that practices currently could not provide owing to a lack of capacity. As previously discussed, the opinion of physicians also depended on the profession fulfilling the role of patient navigator. Ferrante et al. (2010) used social workers as care navigators and a strong focus on social services was noted. It was identified that

different types of patients would be referred to a patient navigator with a nursing background than one having a social work background (Ferrante et al., 2010).

At the level of care navigators, the study by Ferrante et al. (2010) showed that some care navigators found managing their role as navigator whilst being trained as a social worker not always easy. It was found to be challenging to balance the boundaries they had as a navigator (e.g. pointing people in the right direction) and the work they would do as a social worker (e.g. securing that the patient received all of the needed services). It became clear that care navigators found 'older people' to have different needs; *'some can just run with it, but elderly are not able to go out on their own'* (Ferrante et al., 2010:740). In these cases, care navigators mentioned that *'as a social worker they would have gone further…'* and that *'the role as a care navigator needed to be more limited and on occasion what the patient needed was a social worker'* (Ferrante et al., 2010:740).

At an economic level, the results were seemingly mixed and ambiguous. Some programmes mentioned positive economic outcomes (including cost-effectiveness), but others showed little or no effect (Albert, 2012; Ferrante et al., 2010; Yao et el., 2012). The results of the latter could have been caused by difficulties in proving long-term effects and the possibility that financial savings might not be seen at primary care level but in the utilisation of (secondary) services (Ferrante et al., 2010). These issues were considered to need further consideration. Much of the literature was drawn from the US; a Health Maintenance Organisation model of care with health care provided based on insurance. In some of the studies patients were asked if they would be prepared to pay privately for the care navigator service, if it was not included as part of their insured care. Patients reported that they either could not pay for the services or felt that, although useful, most of them would not pay for these extra services. Physicians stated that they would like to have the patient navigator, but would not be able to in the current payment environment (Ferrante et al., 2010).

3.3 The way forward in care navigation for older people with multimorbidity

This section moves beyond the results from the scoping review by placing them into the wider research context. It further highlights some of the foundations for this doctoral research, based on the literature from the scoping review. For example, it was the finding of in-person care navigation issues (see section 3.3.1) that fostered the focus to further explore digital care navigation support.

3.3.1 In-person care navigation versus digital support

Ensuring timely, appropriate, affordable and quality care, requires smooth navigation through the care system (Ramalingam, 2010). When navigation was too burdensome for patients, overuse, underuse and inappropriate use of services was reported. Patients delayed care or failed to get the needed care and sought care in inappropriate but more easily accessible settings (Albert, 2012; Bahandari and Snowdon, 2012; Jackson et al., 2012). Such care navigation issues could potentially inhibit the capacity (e.g. patients' ability to self-advocate) of certain individuals more than others (Willis et al., 2016), which may increase or lead to health disparities (Huber et al., 2014; Natale-Pereira et al., 2011).

According to Ferrante et al. (2010), four major challenges came with navigating the complex health care system: (1) choosing, using and understanding health coverage or applying for assistance when uninsured; (2) choosing, using and understanding different types of health providers and services; (3) making treatment decisions; (4) and managing care received by multiple providers.

Primary care has been expected to assist patients with all of these elements (Ferrante et al., 2010). Three out of four patients in the study by Jackson et al.

(2012) reported that their GP managed their care and held the responsibility for referrals. A high frequency of contacts with the GP was noticed, but the strength of relationship was not investigated, nor were the effectiveness and efficiency of such increased GP appointments. Taking up care navigation tasks in order to help patients find their way was often impossible in primary care due to time, personnel and reimbursement constraints (Ferrante et al., 2010). This questions the sustainability of such initiatives to support those with LTCs in the primary care setting. Moving forward, Rein (2007) pointed out three primary questions to develop a research agenda that will help to better understand patient navigation:

a) Where should we focus our attention? The primary care provider is seen as the de facto coordinator of care, but also larger multidisciplinary groups can be explored. So navigation would be looked at both within and between complex institutions.

b) Which patients should the attention be on?

c) Which points in the health care sector should be areas of focus?

He further explained the difficulties related to health care navigation (Rein, 2007). Providers, both individuals and organisations, needed to both specialise and coordinate. The combination of these two aspects and especially the lack of the latter (coordination), made navigation the difficult and burdensome task it seemed to be for patients. Most of the efforts so far tried to help patients to deal with obstacles in the existing system. Rethinking or redesigning the whole picture or bigger system was rare (but under exploration). According to the report, patient navigation problems and consequences could only be fully addressed by system-level interventions (e.g. group appointments or medical teams truly constructed around the patients' needs). However, some steps in between should be taken (e.g. structural innovation, improved communication and information sharing).

Thus far, the health care system has assumed that with some guidance consumers would 'figure it out' for themselves (Rein, 2007). Not only did this hold the risk that they might not successfully do so, but it also increased the risk of inefficient wayfinding and could be daunting and unpleasant to consumers. As our society is challenging the existing care delivery structures, further research is inevitable. The introduction of professional and lay navigators to assist patients within specific domains of care (in particular cancer care) has happened (e.g. Meade et al., 2014). They helped patients with accessing and using services as well as providing psychosocial support. The evidence within the cancer setting demonstrated that it helped to overcome perceived barriers to care (Huber et al., 2014; Natale-Pereira et al., 2011). The evidence, with regard to improvement of patient outcomes or facilitation of patient navigation, outside this setting was however limited, and the need for further research to value the proposition of such navigators is desired.

3.3.2 Navigation in a patient-centred care model

The need for better care integration emerged from this scoping review. Integration has been described on a continuum (i.e. some components of the care system are better integrated than others), but was not always well-defined in the literature (Jackson et al., 2012). Common elements of integration included: comprehensive services across the care continuum, patient focus, geographic coverage, standardised care delivery through interprofessional teams, performance management, information systems, organisational culture and leadership, physician integration, governance structure and financial government.

According to Jackson et al. (2012) four key change strategies were central to integration: providing people-centred care, reducing clinical variance, organising the care continuum, and process improvement. Factors affecting coordination, collaboration and integration were co-location, lack of appropriate office space for

patient navigators, and dividing time over different practices (Ferrante et al., 2010).

When examining health and social care delivery, it is essential to take the environment (in which patients seek and receive care) into consideration. From the challenges that came with navigation, the elements of integration as well as the rest of this scoping review it became clear that person-centred care was invaluable for patients. Involvement and partnership in care were key assumptions underlying the concept of person-centred care (also see Chapter One, section 1.1.3). However, based on Ravenscroft's (2010) findings, participation seemed to be the result of active efforts from the patient and not the result of the system supporting patients in this idea of person-centred care.

3.3.3 Technological support for care navigation

The care system showed several commonalities with other public services. In business terms, service design (and delivery) is believed to have an impact on how services are perceived, experienced and even adopted. People with LTCs could be seen as consumers or users of care services. Service design of a hospital should not start at the point the patient enters the hospital, but at the point at which someone starts to feel unwell. As with other services, customer experience is at the core of care service design because of its direct impact on customer satisfaction. Experience-centric services (such as health care) need to enable the individual to connect with the service in a customised, personal, meaningful and memorable way (Bhandari and Snowdon, 2012).

The focus of several projects on patient navigation in this scoping review was on patient empowerment and patient assessment information. A few recent studies explored opportunities of technology to share, for example, up-to-date information (Manderson et al., 2012). Having an electronic tool to support

patients in the task of navigation, might indeed decrease the pressure on primary care. Although the numbers of digital use are increasing, they still tend to be lower amongst the current older-old (85 years and over) (Brossoie et al., 2010; Orlov, 2016). However, the baby boomer's generation already show higher adoption rates (Brossoie et al., 2010; Green and Rossall, 2013). Looking at this more technological side and how this might support navigation, the design and accessibility of user interface was found to be a critical element. Regarding the adoption of technology in health care, most research has focused on the implementation and adoption of health information technology (Bhandari and Snowdon, 2012). Although these were important factors, evaluating the acceptance or rejection of technology applications by end-users would be critical. Without acceptance, adoption cannot take place. An experience-centric service design was expected to have positive impact on the user's acceptance and adoption of technology (Bhandari and Snowdon, 2012).

3.4 Conclusion

As the size of the older population increases and people are living longer, the demand for information on how to navigate and cope with issues faced in later life, is expected to increase even further (Brossoie et al., 2010). The idea of using care navigators to help patients with these aspects was initially introduced in the cancer setting (Huber et al., 2014; Willis et al., 2016). Efforts to address navigation challenges have been successfully implemented in other settings and care managers exist for specific diseases. Care navigation programmes have been shown to enhance patients care journeys, improve their satisfaction and potentially reduce costs in the long term (Albert, 2012).

Care navigation is now gaining traction in health systems, community-based health initiatives and primary care practices. Clinically skilled care navigators

provide a bridge between appointments with physicians. They try to meet patients' care needs and help them keep on track (Albert, 2012). Limited research is available on the use of care navigators in the primary care setting (Ferrante et al., 2010). The primary care setting is a unique environment in which a variety of health and social care issues form the reasons for encounter. With the changing population, the different care needs this brings along as well as evolutions in the care system (increase in specialisation), the role of care navigators in primary care tends to be challenging (Ferrante et al., 2010).

Projects have focused on ICT to help clinicians in the tracking and monitoring of patients. Less effort has gone to actually help patients navigate their care pathway (Ferrante et al., 2010); nonetheless ineffective navigation was reported to lead to poor outcomes and inefficiencies (Ferrante et al., 2010). Providing this support to patients, the tools to enable them to play an active role in their care plan, is fundamental to person-centred care (see Chapter One).

In his paper, Albert (2012) pointed out five elements that can help a system to change the care delivery process within the context of using care navigators. He detailed how one should determine areas of risk, identify a target population, find the right staff to support the model, outline protocols and expand the scale of the programme. Patients with multimorbidity are known to have multiple providers involved in their health and social care, all of which seem limited connected with each other (Jackson et al, 2012; Ravenscroft, 2010). The complexity of the care system and thus finding their way through these separate parts of the system (Ravenscroft, 2010) is a current problem for patients with multimorbidity.

To address these current gaps, three objectives were identified for this thesis (see sections 1.2.3.1 and 2.4.3). This chapter addressed the first objective of the thesis by synthesising the literature on care navigation among older people with multimorbidity from a patient perspective. Although the scoping review revealed

the types of support these patients need, it remains unknown in which way this should be delivered. Vague ideas on roles and tasks regarding care navigators exist, but it is unclear what patients prefer. In other words, the use of patient navigators or other support in navigating the care system has not been fully explored in the context of multimorbidity. Most research focussed on particular points on the care continuum (e.g. transition from hospital to home), specific conditions (e.g. COPD) and/or significant events (e.g. post stroke). The way in which the role of care navigators was fulfilled appeared to differ according to the goals of the study, the type and severity of the condition (Manderson et al., 2012). Implementing this role of care navigators in the primary care setting was challenging (Ferrante et al., 2010). Most positions and roles further seemed to be part of a larger (multidisciplinary) team (Manderson et al., 2012).

These difficulties, that might be peculiar to the setting of multimorbidity or primary care, fostered the idea to explore other options (i.e. ICT in this thesis). For example, whether ICT could support individuals in the task of navigating their way through a care system (i.e. a GPS for the care system). Such a 'tool' could be argued to be essential given that the care system is (and has been) characterised by dynamic changes that can occur quickly and often with little consultation (e.g., see Timmins 2012). Thus, the need for navigation is frequent, with some elements being dealt with in an automatic manner (e.g., prescription). Coleman (2003) identified technology as a route to, on the one hand capture such dynamic and rapid changes and on the other hand cope with parts that could be automated. As such, technology could be one way to mitigate the ongoing health and social care 'churn'. However, implementing ICT systems to support care is also seen as costly and a balance between information needs and protection of privacy is required (Coleman, 2003).

In addition, it is unclear what the care network of people with multimorbidity exactly looks like, who they get support from, etc. and thus what care navigation

for this group involves. All of these are conditions that need to be fulfilled and thus known before one can think about how to 'support' these patients. These elements are addressed in the second (analyse and visualise the structures of and interactions in the PCN of older people with multimorbidity and gain an understanding of their experience of navigating their PCNs) and third objective (identify elements for improvement in care navigation among older people with multimorbidity and deliver design requirements for the development of an ICT tool to support this population in their navigation through the care network) in Chapters Four and Five.

4

Analysing and Visualising Personal Care Networks

Prior to establishing ways in which technology could support older people with multimorbidity in the navigation through their PCN, a comprehensive experience-centred understanding of their PCN was needed. It was necessary to employ a research method that allowed visualisation and analysis of the formal characteristics of relationships between people. Social network analysis (SNA) is a well-established tool, used precisely to better understand characteristics of social relationships such as frequency and direction of communication (Scott and Carrington, 2011).

The first part of this chapter summarises underpinning ideas, definitions and terminology used in SNA and relevant to this thesis. These SNA concepts are linked to examples of this particular study. In the second part, this chapter describes the two separate, but related, methods used to analyse PCN data. This section relates to the best practice in constructing SNA questionnaires and semi-structured interviews and the pilot work carried out to validate the instruments used as outlined in Chapter Two.

The third, and final, part of the chapter combines the results, presenting findings in relation to the following research questions:

- Who is involved in the PCN from a patient perspective?
- Why are they involved in the PCN according to the patient?

Results relating to experience, barriers and facilitators of care navigation are reported in Chapter Five (see section 5.3).

4.1 Introduction to social network analysis

4.1.1 Social Networks: people connected to people

Social networks, especially in a digital era, could have different connotations. This thesis followed the initial description of **social networks** by Fischer (1982):

"Sets of people with whom an individual is directly involved" (Fischer, 1982:2).

Another definition of social networks was found in the work of Wasserman and Faust (1994). They referred to a social network as a set of people that is tied by one or more types of relations (Wasserman and Faust, 1994).

Social networks have been reported to differ in the extent of connections or people involved in the network, their homogeneity, the geographical proximity and the frequency of contact with people in the network (Ashida and Heaney, 2008). Apart from the initial, and relatively automatic, connections people have, (for example, with blood relatives), over time people construct their own social networks. The networks people build throughout their lifespan are based on functional characteristics such as social support, social influence or social comparison (Ashida and Heaney, 2008).

In essence, people connect and interact with other people. The basis or reasons for these interactions vary and can, for example, originate from a shared interest (e.g. being part of the same sport team), employment at the same company or following the same lectures. Borgatti et al. (2009) identified four main categories based on which relationships form between people: similarities, social relations, interactions and flows. Relationships resulting from *similarities*, include two

people having shared attributes, for instance attitudes. *Social relations* refer to commonly defined role relations such as kinship or friendship. *Interactions* are behaviour-based relationships that can include speaking with or helping someone. Finally, *flows*, are relations based on exchanges or transfers between people (e.g. information, influence or resources). The latter two, flows and interactions, were of particular interest for this thesis (see section 4.1.3) as it aligned with the second research objective around *'analysing and visualising the structures of and interactions in the personal care network (PCN) of older people with multimorbidity and gaining an understanding of their experiences of navigating their PCNs'* (see section 2.4.3).

In 1991, Scott noted that SNA was an appropriate way to analyse and visualise this relational information, i.e. data on relationships between people (Scott and Carrington, 2011). As the interest in social networks (and SNA in particular) grew, researchers developed a terminology to refer to the different elements in the social network. Generally, the people (individuals or groups) comprising the social network are called actors. The connections between the actors are referred to as ties (Scott and Carrington, 2011).

4.1.2 Analysing social networks

SNA starts from the premise that social life is mainly and most importantly created by relationships and the patterns formed by these relationships (Scott and Carrington, 2011). In care settings, SNA has for example been used to describe and understand the social aspects of communication patterns (Dunn and Westbrook, 2011), to investigate the impact of social capital on health and wellbeing (Cattell, 2001), to look at the influence of social networks on frail older people's life satisfaction (Berglund et al., 2016), and to gain an understanding of the occurrence of obesity among youth (Valente et al., 2009).

Only one study in the care setting used SNA in a similar way as this doctoral research. Cheong et al. (2013) applied egocentric SNA to gain an understanding of the patients' role in multidisciplinary care (MDC) by describing patients' health networks; comparing different patient groups (community and clinic); identifying the role of pharmacists in the patient network and developing an understanding of the interactions in the patient network. Cheong et al. (2013) focussed on patients with asthma and collected network data mainly through the use of interviews. Patients were asked about the different carers involved, their position in the network and asthma symptoms (Ibid). Data regarding the latter was collected via an asthma questionnaire. The position of actors in the asthma care network was established providing patients with a circle diagram (similar to Figure 21 on p.175) and asking them to place the different carers on the circles during the interview (Cheong et al., 2013).

Some commentators have argued that SNA is not a theory, nor a methodology, but a perspective; it provides a way of looking at a problem (Scott and Carrington, 2011). With the growing interest in analysing and understanding social networks, the number of definitions of SNA has expanded. Serrat (2010) defined **social network analysis** as follows:

> *"Social network analysis seeks to understand networks and their participants and has two main factors: the actors and the relationships between them in a specific context" (Serrat, 2010:1).*

A few other examples of definitions include:

> *"Social network analysis is the study of social structures and its effects. It conceives social structure as a social network; that is, a set of actors (nodes) and a set of relationships connecting pairs of these actors" (Tindall and Wellman, 2001:265-266).*

"Social network analysis is the mapping and measuring of relationships and flows between people, groups, organisations, computers and other information/knowledge processing entities" (Krebs, 2000, cited in, Dalkir, 2005:116).

Although the wording of these descriptions differs, they all include two main components: 'actors' and 'relationships'. Actors in SNA are represented by points and referred to as **nodes**. An enlarged basic image of this can be found in Figure 12. Nodes are the individual units that are connected by the relations (ties) whose patterns are studied. Any unit that can be connected to another unit can be studied as a node in SNA, however most frequently these are people or organisations. The ties (relationships) or **edges** in SNA are represented by lines (see Figure 12) and can display friendships, collaborations, information flows, et cetera., basically any possible connection between the nodes can be of interest.

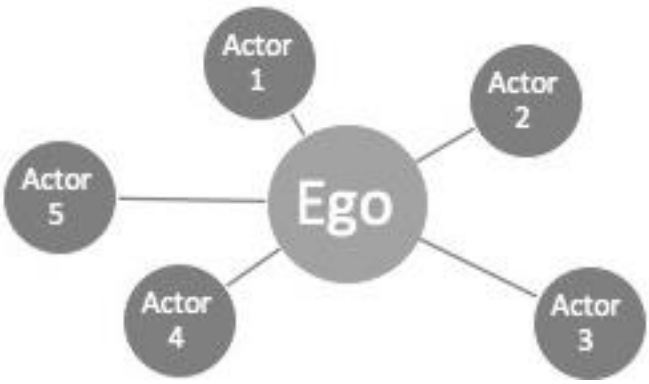


Figure 12: Enlarged image of a network graph with nodes and their edges

In order to support the analyses of these structures, SNA uses two types of tools from mathematics to represent the information: graphs and matrices (Hanneman and Riddle, 2005). **Graphs**, also called sociograms, are in this case visual representations of a social network (Ibid), as shown in the simplified example in Figure 12. **Matrices**, or sociomatrices, are the numerical output of network information (Hanneman and Riddle, 2005), showing information on the density of the network, number of actors involved, et cetera (Figure 13). Particularly, the use

of sociograms was found invaluable for this research. In this doctoral study, the use of sociomatrices, often paramount in sociocentric SNA (see section 4.1.4), was complemented with statistical testing in SPSS (IBM Corp). This was found to reveal more relevant information for the study's egocentric approach (see section 4.1.4) and to address the subsidiary research questions set up for analysis (section 2.4.3).

Density Measures

	1 Size	2 Ties	3 Pairs	4 Densit	5 AvgDis	6 Diamet	7 nWeakC	8 pWeakC	9 2StepR	10 ReachE	11 Broker	12 nBroke	13 EgoBet	14 nEgoBe
1	4.00	11.00	12.00	91.67	1.08	2.00	1.00	25.00	100.00	29.03	0.50	0.04	0.00	0.00
2	7.00	24.00	42.00	57.14	1.43	2.00	1.00	14.29	100.00	18.75	9.00	0.21	8.17	19.44
3	6.00	17.00	30.00	56.67			1.00	16.67	100.00	23.08	6.50	0.22	8.25	27.50
4	4.00	11.00	12.00	91.67	1.08	2.00	1.00	25.00	100.00	28.13	0.50	0.04	0.33	2.78
5	8.00	29.00	56.00	51.79	1.57	3.00	1.00	12.50	100.00	16.98	13.50	0.24	14.67	26.19
6	3.00	2.00	6.00	33.33			1.00	33.33	100.00	42.86	2.00	0.33	1.00	16.67
7	3.00	6.00	6.00	100.00	1.00	1.00	1.00	33.33	88.89	36.36	0.00	0.00	0.00	0.00
8	6.00	24.00	30.00	80.00	1.20	2.00	1.00	16.67	100.00	20.45	3.00	0.10	0.00	0.00
9	3.00	6.00	6.00	100.00	1.00	1.00	1.00	33.33	100.00	36.00	0.00	0.00	0.00	0.00
10	5.00	16.00	20.00	80.00	1.20	2.00	1.00	20.00	100.00	23.68	2.00	0.10	0.33	1.67

1. Size. Size of ego network.
2. Ties. Number of directed ties.
3. Pairs. Number of ordered pairs.
4. Density. Ties divided by Pairs.
5. AvgDist. Average geodesic distance.
6. Diameter. Longest distance in egonet.
7. nWeakComp. Number of weak components.
8. pWeakComp. NWeakComp divided by Size.
9. 2StepReach. # of nodes within 2 links of ego.
10. ReachEffic. 2StepReach divided Size.
11. Broker. # of pairs not directly connected.
12. Normalized Broker. Broker divided by number of pairs.
13. Ego Betweenness. Betweenness of ego in own network.
14. Normalized Ego Betweenness. Betweenness of ego in own network.

Figure 13: Egocentric network analysis matrix (Hanneman and Riddle, 2005)

It was the underlying structure of actors (e.g. care providers) and their relationships with the patient (e.g. informal care through emotional support) that were of interest to answer the question: *'What does the care network of older people with multimorbidity look like?'* This study chose to focus on the formation and structure of the PCN from a patients' perspective (also see section 4.1.4). It was this patients' view on who to select to be part of their PCN and the reasoning behind it that was explored.

4.1.3 Boundaries in social network analysis

Defining which nodes to include is one of the early challenges when conducting SNA (Scot and Carrington, 2011). In 1983, Laumann et al. proposed three main approaches to aid this decision. Firstly, *a position-based approach* that only includes those actors that hold a particular position (e.g. all practicing GPs in the East Midlands) and thus those who do not hold this position are excluded.

Secondly, researchers opting for *an event-based approach* would define the population based on who participated in a particular event of interest (e.g. all patients that attended free flu vaccination). Finally, adopting *a relation-based approach* starts with a small number of nodes within a population of interest and extends these to include others who share particular types of relations with those nodes. It was this third approach that was of particular interest to this study, starting with the individual older person with multiple morbidities and expanding his/her network based on who they were in contact with for their care.

Once the focus of the nodes was decided upon, the relations or ties between these nodes needed to be identified. The previously mentioned (section 4.1.1) classification of Borgatti et al. (2009) aided this decision process. To study the care networks surrounding older people with multimorbidity, two of Borgatti et al.'s (2009) categories were of particular interest: interactions and flows. In relation to interactions, the current study looked at which actors older people with multimorbidity were in contact with for their care. As with regard to flows, an understanding was sought on the type of information patients and actors exchanged as well as the type of support (informational, emotional or care) patients received from them.

4.1.4 Type of social network analysis

A final fundamental decision regarding the type of SNA had to be made before considering the details for data collection. The reason for deciding on the type of SNA early on laid in the fact that the two main types of SNA are distinct both in terms of sampling and data collection. The focus of SNA, as well as its evolution, resulted in the adoption of SNA, in the main, as a tool to explore social structures from a 'bird's-eye view'. Analysing all nodes rather than zooming in on any particular node became common practice and is referred to as *sociocentric network analysis*. However, this is not the only method to study networks. Instead

of capturing the overall picture, some researchers began to focus on just one node, the ego. In *egocentric network analysis* the ego, its surroundings and relations with other nodes (often called **alters** in this type of SNA), dominates the analysis (Scott and Carrington, 2011).

This doctoral research was underpinned by theories around patient-centred care, patient empowerment and UCD (see section 2.4.1). All three these theories emphasised the central position of the patient/user. In line with these theories, and thus the Patient-Centred-Design conceptual framework (see section 2.4.2), and the research questions, the patient was put at the heart of the SNA. As a result, the PCN surrounding the patient was explored from the patient's perspective and therefore an egocentric view of SNA was applied. The patient with multimorbidity took the 'ego' position and the relationships s/he had with people (alters) supporting him/her in their care (i.e. their personal care networks) were explored from the patients' perspective. In particular, data were needed on: 'who' is involved in their care network; 'why' and 'how' are these people involved; and 'what' did this involvement look like. At the point of data collection for this study, no previous studies had provided these types of data and no existing instruments were found suitable to collect them (see Chapter Two, section 2.5.2, for the construction of the questionnaire and interview topic guide).

4.2 Analysing egocentric network data

4.2.1 Analysing the quantitative PCN data in this study

Two main techniques were used to analyse the questionnaire data. In the first instance, the data allowed *descriptive analysis* using SPSS Statistics V22 (IBM Corp). This further enabled an exploration of the PCN data according to different groups (e.g. people aged 55-65 years versus those aged over 65 years). It should

be noted that in carrying out these sub-analyses, the numbers of participants became relatively small and thus results should be interpreted carefully. Secondly, Gephi 0.9.1 (Mathieu et al., 2009) was used as *visualisation and exploration* software assisting SNA and providing sociograms of the PCNs.

The quantitative data from this study were collected and analysed in the context of the second study objective (see 2.4.3): *Analyse and visualise the structures of and interactions in the personal care network (PCN) of older people with multimorbidity and gain an understanding of their experiences of navigating their PCNs* (see Chapter Four). Five subsidiary questions were explored in the analysis:

a) Which actors are involved in the PCN of older people with multimorbidity and from which care domain (social care community, health care community, health care hospital and informal care)? See section 4.3.2
b) Does this structure of the PCN differ according to the number of LTCs, age and sex? See section 4.3.3
c) Why are these actors present in the PCN of older people with multimorbidity? See section 4.3.4
d) Does this reason for involvement differ according to the number of LTCs, age and sex? See section 4.3.5
e) How are actors involved in the PCN of older people with multimorbidity? See section 4.3.6

The questionnaire was designed to ensure the above research questions could be responded to as well as allow an investigation of the PCN from different angles: (1) the importance of actors, and (2) actual contact with actors, (3) the reasons for this contact, and (4) the type of support provided. Four domains of care were investigated: health care actors in the community (HCC), health care actors at the hospital (HCH), social care actors in the community (SOCC) and informal care

actors (IC). For each of these domains participants were asked to indicate on the predefined list (e.g. GP, medical consultant, social worker, partner) who was *important* to them in their PCN and who they had *contact* with. If participants indicated contact with a particular actor, information was gathered on the type and frequency of the contact, what type of support they received, and their satisfaction with that provider/service. The final composition of these questions is illustrated in Figure 14.

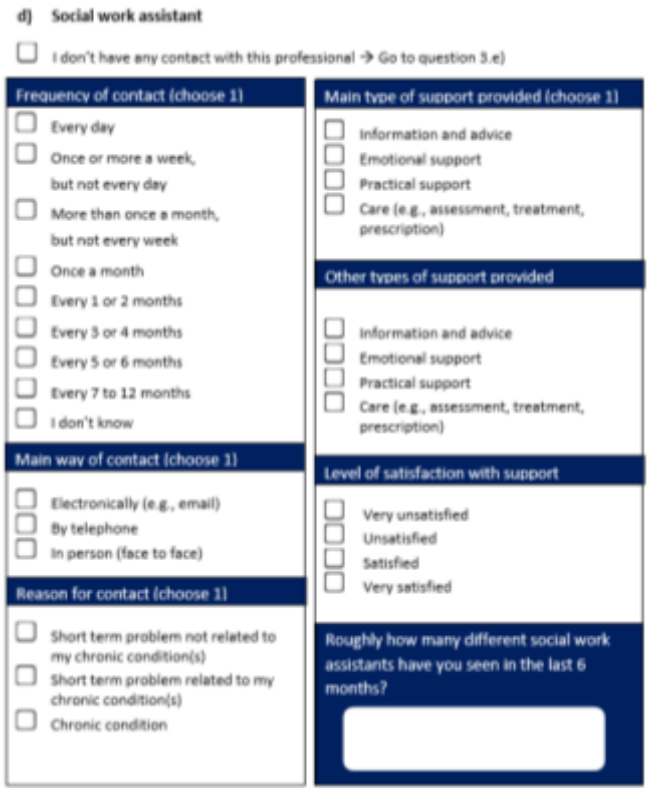


Figure 14: Example of questionnaire section

Overall, the questionnaire data ensured two different approaches were possible in the analysis. Firstly, analysing information on whether (yes) or not (no) someone was perceived important in the PCN. Secondly, by taking into account all the actors important to the participant and establishing an overall image for the number of actors perceived as important in relation to SOCC, HCC, HCH and IC. For example, if the 'total' number of the HCC actors important to the participant was 'four', this

suggested that the participant indicated four actors (e.g. GP, GP nurse, pharmacist and chiropodist) in HCC to be important.

4.2.2 Analysing the qualitative PCN data in this study

Interview data have a different analysis process compared to data deriving from quantitative research. Data tend to be rich in detail and intertwined in content (Ritchie and Lewis, 2003). In addition, unlike quantitative data, rules for analysing interview data are often vague, and approaches vary (Neale, 2016; Silverman, 2013). Bearing these differences and variations in mind, qualitative researchers in social science aim to capture, portray and explain the social worlds of the people they are studying (Ritchie and Lewis, 2003).

The analysis process is affected by its goal and thus a decision had to be made regarding the goal of analysis. This goal can differ according to the 'tradition' (e.g. ethnography, content analysis) and/or research discipline (Ritchie and Lewis, 2003). Some analytic techniques and traditions are used across disciplines (e.g. thematic analysis and grounded theory); others are more discipline specific (e.g. interpretative phenomenological analysis in psychology) (Rapley, 2011). Three common goals for qualitative analysis have been distinguished (Smith and Firth, 2011:54):

- Methods that explore the *use and meaning of language* (e.g. discourse analysis)
- Methods that focus on the *development of a theory* (e.g. grounded theory)
- Methods that *describe and interpret* participants' views (e.g. thematic analysis)

In this thesis, the main goal was to describe and interpret the patient's views. Along with thematic analysis, framework analysis has been reported as an

appropriate approach to achieve this (Smith and Firth, 2011). Both (thematic and framework analysis) share similarities and look for commonalities and differences in the data (Gale et al., 2013). Thematic analysis has been widely used in health- and social care research. More recently, framework analysis is gaining popularity and perceived to sit within the broader family of thematic analysis (sometimes called qualitative content analysis) (Gale et al., 2013; Seale, 2012). In other words, framework analysis is a specific type of thematic analysis, usually with greater emphasis on the transparency of the analytical process (Smith and Firth, 2011) and linkage between the stages of analysis (Braun and Clarke, 2006). In this doctoral study, an integration between qualitative and quantitative data was pursued. As Seale (2012) pointed out, one of the main advantages of framework analysis lies exactly in its competence in making a clear match with themes in the quantitative analysis. Framework analysis was selected as the method of analysis owing to: its ability to enhance rigour in the analytical process (Ritchie and Lewis, 2003 in Smith and Firth, 2011); increase the transparency of analysis (Gale et al., 2013; Seale, 2012; Smith and Firth, 2011); the systematic and structured approach (Gale et al., 2013; Seale, 2012; Smith and Firth, 2011); and the advantage of facilitating links to quantitative data (Seale, 2012). This choice also benefitted the intended practical outcome of this study (i.e. providing the design team with a structured document that communicates the requirements needed and the users' experience).

Framework analysis originated from policy research and has been used since the 1980s (Gale et al., 2013). Applied research and projects set up to inform policy typically had short time frames and benefitted from a theoretical or applied framework to guide the analysis (Seale, 2012). As with thematic analysis, framework analysis is an inductive, iterative and continuous process. It allows concepts to emerge as one progresses through the analysis process. However, at the same time, researchers have a clear understanding of the purpose of the

research and the question that needs answering (Flick, 2013). As such, a more systematic and transparent approach of data analysis can be applied.

The software used to support data analysis in this study was discussed in section 2.5.4. Framework analysis of the qualitative data was supported by Excel and NVivo version 10. The final and completed framework with examples quotes can be found in Appendix 7.

In this study, the recordings of the semi-structured interviews were transcribed verbatim. In addition, field notes were made during the conduction of the interviews. Based on the underpinning conceptual framework of Patient-Centred-Design (see section 4.2.2), the interview guide (see section 2.6.1.2), an initial exploration of the quantitative network data, the interview transcripts and the field notes; seven themes were identified for the framework (see section 4.2.2.2). Table 9 shows the skeleton of the framework that was set up for the coding and analysis of the interviews. This skeleton then functioned as an overall framework for further coding and data analysis of the qualitative and quantitative data. Appendix 7 provides example quotes from the interviews for each theme in the framework.

4.2.2.1 Coding process of qualitative data

Although analysis of the qualitative data was an iterative and reflective process, three different stages could be distinguished. These stages were not necessarily linear in progression and moving between different stages was not uncommon.

In the first instance, the transcripts were line-by-line coded. This process was assisted by NVIVO and resulted in several open codes (e.g. difficulties finding the 'right' person to contact, perception of limited communication between providers) that were later grouped together as categories (e.g. barriers in care navigation) and supported the themes from the framework (see Table 9).

Secondly, both within and between transcripts, a search was conducted for remarkable and noticeable differences and similarities between participants (e.g. patients with family living nearby versus those with family further away). Thirdly, reoccurring codes, differences and similarities were grouped and brought together as subcategories within the seven themes (see Table 9 and the next section) of the framework.

4.2.2.2 Framework for qualitative analysis

The final seven themes of the framework derived from three main sources:

a) The three objectives of this study (see section 4.2.3)
    - Synthesise the literature on care navigation among older people with multimorbidity from a patient perspective.
    - Analyse and visualise the structures of and interactions in the personal care network (PCN) of older people with multimorbidity and gain an understanding of their experiences of navigating their PCNs.
    - Identify elements for improvement in care navigation among older people with multimorbidity and deliver design requirements for the development of an ICT tool to support this population in their navigation through the care network.
b) The topic guide (see section 2.6.1.2), and thus the Patient-Centred-Design framework (see section 2.4.2)
c) The interview transcripts

The first theme, **meaning of the PCN**, derived from quotes that described the PCN. Within these descriptions, three distinctions were found that created subsections for the framework: formal and informal care; NHS and private care; primary, secondary and tertiary care. These subsections emerged immediately from the

transcripts. The results relating to this first theme of the framework are provided in section 4.3.1.3.

The second theme, **structure of the PCN**, involved quotes both about the shape of the PCN (which referred to the SNA graphs of the participant) and changes that took place in the PCN (e.g. over time). This, and the third theme allowed for connections between, and later integration of, the qualitative and quantitative data. This theme and the next one (roles and responsibilities – see below), were added to the framework as a result of the research questions and objectives of the thesis. Results of these theme can be found in section 4.3.2.1.

The third theme, **roles and responsibilities**, comprised seven subsections in the framework to allow the analysis of different actors in the PCN. The patient, community, family, friends, primary care, experts or hospital care and organisations or third sector care emerged from the data. As with the second theme, this theme arose from the objectives set for this doctoral study. The study results in relation to this theme are discussed in section 4.3.2.2 and 4.3.4.

Another theme related to the **first point of contact**, which included quotes on contact points in the PCN and the wider system. This theme was added to the framework as a result of the scoping review and the research objectives. It was felt that gathering information on 'where patients go in first instance' would add to the care navigation picture. The result section 4.3.4 reflect on the data for this theme.

Service organisation and operation, the fifth theme in this framework, looked at the internal organisation (e.g. within the same setting), the external interaction (e.g. referral), the PCN and the wider system (e.g. communication between settings). This theme arose from the transcripts, the study objectives and the Patient-Centred-Design conceptual framework. Together with the next theme (PCN interaction and communication), it was felt that quotes relating to service

organisation and operation highlighted some of the barriers in patient navigation and thus elements that could be improved. Chapter Five, section 5.3.2.2 discusses the results of this fifth theme.

The next theme related to this by detailing analysis on **PCN interaction and communication**. Data were found for both patient-provider and provider-provider interactions. An important focus was put on this theme as it further revealed data on elements that could be improved (third study objective). Section 5.3.2.3 reflects on the data from this study in relation to this theme.

The last theme, **technology**, explored the data in terms of technology in the care system (e.g. websites used for disease-management) and the personal use of technology. The latter allowed for an estimation of the familiarity of the interviewee with technological devices which was important for the translation of the findings in design requirements. This final theme was added to the framework as a result of the study focus on 'technology to support care navigation'. The results of this theme are briefly discussed in this chapter, but greater detail is provided in Chapter Five.

The quotes organised within these themes are integrated with the result section of this chapter (section 4.3) and examples of how the quotes were organised according to the framework are provided in Appendix 7.

Table 9: Framework for (qualitative) analysis

INTERVIEW CODE	THEMES			
	Theme 1: Meaning of the Personal Care Network			
	1.1 PCN description	1.2 Formal and informal care	1.3 NHS and private care	1.4 Primary, secondary and tertiary care
[Insert participant code]	[Insert quotes]	[Insert quotes]	[Insert quotes]	[Insert quotes]
	Theme 2: Structure of the Personal Care Network			
	2.1 Shape of the PCN		2.2 Composition	2.3 Changes in the PCN
[Insert participant code]	See participants' pre and post PCN graph		[Insert quotes]	[Insert quotes]
	Theme 3: Roles and responsibilities in the PCN			

INTERVIEW CODE	THEMES						
	3.1 Patient	3.2 Community	3.3 Family	3.4 Friends	3.5 Primary Care	3.6 Expert care/hospital	3.7 Additional organisations and third sector care
[Insert participant code]	[Insert quotes]	[Insert quotes]	[Insert quotes]	[Insert quotes]	[Insert quotes]	[Insert quotes]	[Insert quotes]
	Theme 4: First point of contact						
	4.1 PCN			4.2 Wider care system			
[Insert participant code]	[Insert quotes]			[Insert quotes]			
	Theme 5: Service Organisation – Operation						
	5.1 Internal (continuity)		5.2. External (referral)		5.3 The PCN		5.4. The wider system

INTERVIEW CODE	THEMES			
[Insert participant code]	[Insert quotes]	[Insert quotes]	[Insert quotes]	[Insert quotes]
	Theme 6: PCN Interaction and Communication			
	6.1 Patient-provider	6.2 Provider-provider	6.3 Services	
[Insert participant code]	[Insert quotes]	[Insert quotes]	[Insert quotes]	
	Theme 7: Technology			
	7.1 Technology for/in care	7.2 Personal use of technology		
[Insert participant code]	[Insert quotes]	[Insert quotes]		

4.3 Results: analysis of structures and roles in the PCN

This results section focusses on the research questions around 'structure' of, and 'roles' within, the PCN. Data relating to experience, barriers and facilitators of care navigation are reported in Chapter Five (sections 5.3.1 and 5.3.2).

As described earlier in this chapter and in Chapter Two, this mixed method study applied framework analysis, SNA and statistical testing in order for the data to deliver integrated results, i.e. by combining the quantitative and qualitative data. Section 4.2.2 detailed the process of framework analysis. Although framework analysis was the specific method used for the qualitative data, it also allowed for linkage with, and eventually integration of, the quantitative data as described in section 4.2.2 (also see Table 9) and in Chapter Five.

4.3.1 Sample description

After coding and cleaning, a total of 62 responses to the questionnaire were valid for analysis. A summary of relevant sample characteristics from the questionnaire can be found in Table 10.

Table 10: Summary of questionnaire sample

	N	VALID PERCENT
QUESTIONNAIRE METHOD		
Online	37	59.7
Paper	25	40.3
TOTAL	*62*	*100*
SEX		
Male	28	45.2
Female	14	22.6
Preferred not to say	20	32.2
TOTAL	*62*	*100*
AGE		
55-60	14	22.6
61-65	9	14.5
66-70	7	11.3
71-75	7	11.3
76-80	6	9.7
81-85	7	11.3
86-90	7	11.3
>90	5	8.1
TOTAL	*62*	*100*

	N	VALID PERCENT
NUMBER OF LTCS		
2 LTCs	15	39.5
3 LTCs	8	21.1
4 LTCs	5	13.2
>4 LTCs	10	26.3
TOTAL	*38**	*100*
DIAGNOSIS LTC		
FIRST LTC		
I don't know	0	0.0
Less than 6 months	0	0.0
>6 months, <1 year	0	0.0
≥1 year, <2 years	0	0.0
≥2 years, <5 years	3	8.1
≥5 years, <10 years	14	37.8
≥10 years	19	51.4
Other	1	2.7
TOTAL	*37**	*100*
MOST RECENT LTC		
I don't know	1	2.7
Less than 6 months	4	10.8
>6 months, <1 year	2	5.4
≥1 year, <2 years	3	8.1
≥2 years, <5 years	12	32.4

	N	VALID PERCENT
≥5 years, <10 years	8	21.6
≥10 years	7	18.9
TOTAL	*37**	*100*

*Two questions looked at the number of LTCs participants were diagnosed with. One of the questions specifically asked participants to indicate the number of LTCs they were diagnosed with, the other question asked participants to indicate the types of LTCs they were diagnosed with. A sum of the latter was created and compared with the first question (asking for the number of LTCs). Although the number was equal to or higher than two for both questions (and thus in line with the inclusion criteria), only just over half of the sample (38/62) had a matching number for both questions.

Interviews were conducted with a rough 10% subsample; four women and three men. On average, interviewees were aged 70 years old (ranging from 57-83 years). Demographic details of the interview participants are given in Table 11.

Table 11: Summary of interview sample

PARTICIPANT NUMBER	AGE	SEX	AMOUNT OF LTCS
PP1	83	Female	5
PP2	60	Female	5
PP3	80	Female	5
PP4	61	Female	8
PP5	68	Male	2
PP6	82	Male	4

PARTICIPANT NUMBER	AGE	SEX	AMOUNT OF LTCS
PP7	60	Male	2

4.3.1.1 Demographics of the questionnaire sample

More respondents (59.7%, n=37) used the online link to complete the questionnaire than the paper version (40.3%, n=25). Twice as many women (45.2%, n=28) as men (22.6%, n=14) participated in the questionnaire. Almost one third of the participants (32.2%, n=20) did not reveal their sex in the questionnaire (either missing or 'preferred not to say'). Because of this imbalance, a detailed exploration of the data took place before further analysis. Sex did not show a relationship with any of the variables relevant to answer the research question. With the purpose of statistical analysis being merely descriptive and explorative, after consulting a statistician it was decided not to make corrections for the 2:1 ratio. In what follows, tables, figures and percentages reflect the entire sample unless stated otherwise. On average, questionnaire participants were 72 years old (range 55-94 year).

4.3.1.2 LTCs and multimorbidity in the questionnaire sample

Participants indicated they had been diagnosed with a variety of LTCs including thyroid problems and chronic respiratory conditions. The five most frequently indicated LTCs in the questionnaire are shown in Figure 15.

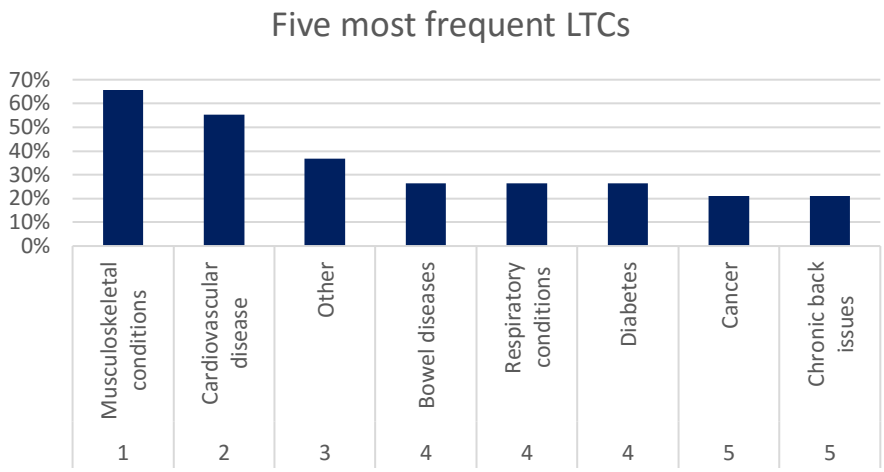


Figure 15: Five most frequently indicated LTCs in the questionnaire

To be eligible for participation (see section 2.6.2), patients had to be diagnosed with (at least) two LTCs. Two questions were analysed to look at the number of LTCs participants were diagnosed with. One of the questions specifically asked participants to indicate the number of LTCs they were diagnosed with, the other question asked participants to indicate the types of LTCs they were diagnosed with. A sum of the latter was created and compared with the first question (asking for the number of LTCs). Although the number was equal to or higher than two for both questions (and thus in line with the inclusion criteria), only just over half of the sample (38/62) had a matching number for both questions. From the participants that had a matching number, the results are reported below.

For 39.5% (n=15/38) of the sample two LTCs were reported, resulting in 60.5% (n=23/38) of the sample with more than two LTCs (Figure 16). On average participants were diagnosed with three LTCs, but as many as nine were reported within one individual. Just over one fifth (21.1%, n=8/38) of the participants was diagnosed with three LTCs and 13.2% (n=5/38) had four LTCs. The remaining, one fourth of the participants (26.3%, n=15/38), were diagnosed with more than four LTCs.

In this study, no significant relationship was found between age and the number of LTCs (r=-0.112, p=0.505) and no significant difference was seen in the sample for the number of LTCs between men and women (F=2.327, t=-1.239, df=24 and p=0.227).

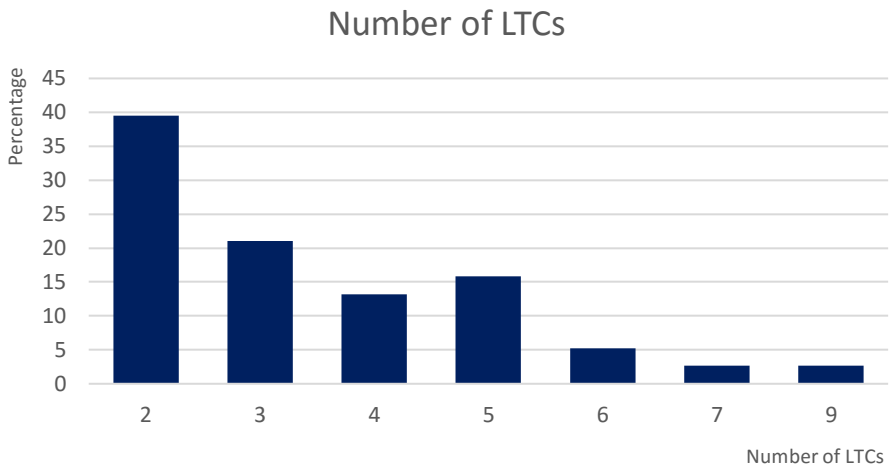


Figure 16: Number of LTCs reported by participants in the questionnaire

All participants reported they had been diagnosed with their first LTC more than two years ago. The majority (51.4%, n=19/37) had their first diagnosis ten or more years ago and 45.9% (n=17/37) had the diagnosis less than ten years ago. Data in relation to the diagnosis of their most recent LTC (i.e. last LTC) showed slightly more variation, with nearly a quarter (24.3%, n=9/37) receiving their most recent diagnosis less than two years ago (Figure 17).

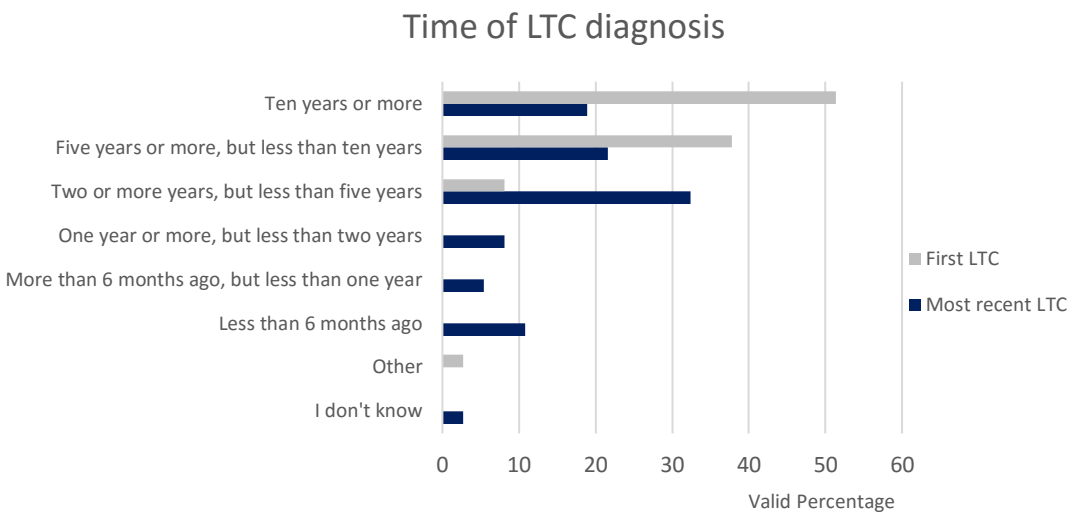


Figure 17: Time since diagnosis of first and most recent LTCs at the time of participation in the study

4.3.1.3 Exploration of the PCN of the sample

In order to explore the structures and features of the PCN, an understanding of 'what the PCN meant' for patients was needed. This information derived from the semi-structured interviews, in particular theme one of the qualitative framework for analysis (see section 4.2.2 and Table 9). Interviewees saw the PCN as a hub or collection of supportive people they were connected with.

> *"To me it means sort of everybody that you're connected with […] family, friends, people I've met and have become friends with since I moved down here, which has been important to me." (pp3)*

Actors (people and services) that were indicated to be part of this PCN are shown in Figure 18 (p.169). It was pointed out that these concerned actors that were 'directly' involved (either found important or in contact with) in the patients' PCN. It did not include administrative personnel (e.g. secretary), support staff (e.g. theatre nurses) or intermediaries (e.g. paramedics).

"[…] my little thing only takes what, 15 minutes, 20 minutes at the most, but it's up to in, include, look at the members of staff that are there to… I've to have hospital transport to get me there, so therefore the ambulance officers has to make that arrangement, there has to come an ambulance driver to come over and fix me, you go to the hospital and see to the receptionist, then they take you into a room to be nurse what have you, you then taken across to the theatre, you got the theatre staff, you got the consultant, you got the registrar, you got those the scrub nurses, you got this that and the other […]. There's just so many people involved for one simple little thing which only takes 15 minutes, but you've you've to add that all up […]" (pp4)

Social network analysis and statistical tests were used to explore what the PCN of older people with multimorbidity looks like. The following questions were set for the quantitative analysis:

a) Which actors are involved in the PCN of older people with multimorbidity and from which care domain (SOCC, HCC, HCH, IC)? See section 4.3.2
b) Does this structure of the PCN differ according to the number of LTCs, age and sex? See section 4.3.3
c) Why are these actors present in the PCN of older people with multimorbidity? See section 4.3.4
d) Does this reason for involvement differ according to the number of LTCs, age and sex? See section 4.3.5
e) How are actors involved in the PCN of older people with multimorbidity? See section 4.3.6

The results in relation to these questions are discussed in what follows. The PCN graphs were produced by Gephi, whereas statistics were supported by SPSS. In addition to the quantitative analysis, and where relevant, qualitative data is

provided in relation to themes two to four deriving from the framework (see section 4.2.2 and Table 9) to enrich the picture. The fifth (service organisation – operation), sixth (PCN interaction and communication) and seventh theme (technology) are discussed in Chapter Five owing to their importance and relevance in relation to the design requirements for an ICT tool to support older people with multimorbidity in their care navigation.

It is important to note that the qualitative and quantitative results of this section need to be interpreted as a whole, but for the purpose of readability and transparency of data analysis they were separated where possible.

4.3.2 Structure of the PCN

4.3.2.1 Which actors are involved in the PCN?

Descriptive statistics and SNA

Across the questionnaires a total of 39 different actors had been reported by participants (Figure 18). Actors closer to the patient and conveying stronger ties (i.e. thicker lines), were more frequently indicated by participants as 'supportive'. Consequently, actors further away from and connected with the patient through thinner ties were overall less indicated by the sample. The closeness or distance of these actors to the patient is also represented by the size of the nodes. Bigger and smaller nodes respectively reflect actors more or less frequently mentioned to be involved in the PCN of participants.

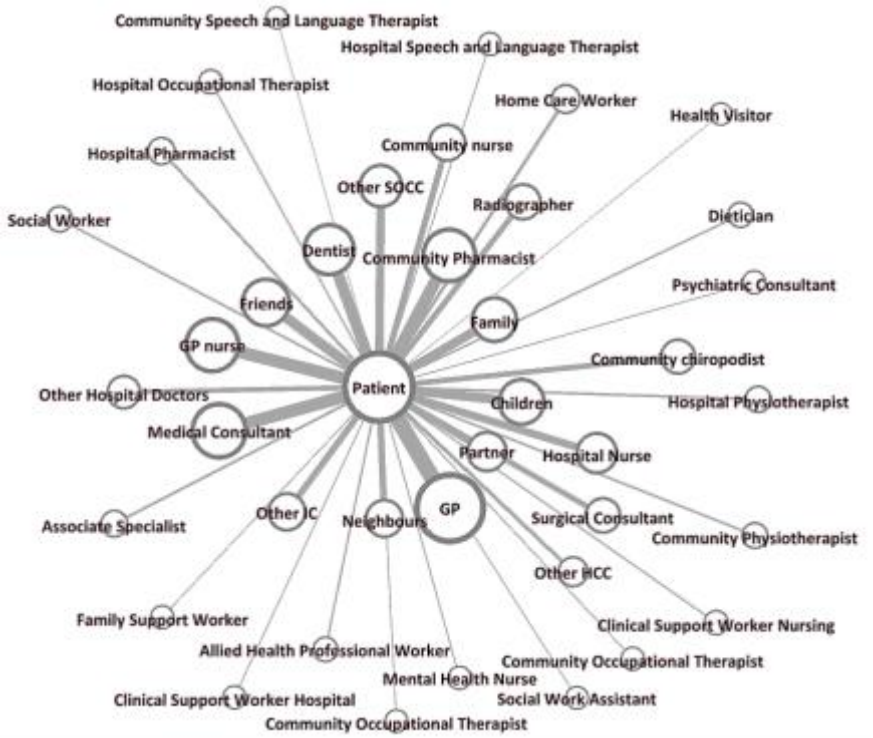


Figure 18: Actors reported to be involved in the PCN

On an individual level, the number of *important* actors varied from as little as one to as many as 20 different alters (i.e. actors in egocentric SNA). Regarding participants' *contact* with actors, similar results were seen but contact with a higher maximum of alters (24) was reported. On average, the PCN of patients contained seven actors. The top five of those most frequently indicated professional actors are given in Table 12.

Table 12: Most frequently indicated professionals in the questionnaire

Top 5 of actors in the domain of HCC	**N**	**Valid %**
GP	39	92.9
GP Nurse	30	73.2
Pharmacist	31	70.5
Dentist	30	68.2
Community Chiropodist	13	28.9

Top 5 of actors in the domain of HCH	N	Valid %
Medical Consultant	31	75.6
Hospital Nurse	17	44.7
Radiographer	14	34.1
Surgical Consultant	9	26.5
Other Hospital Doctors	10	26.3
Top 5 of actors in the domain of SOCC	**N**	**Valid %**
None	30	64.5
Other	15	38.3
Home Care Worker	8	14.3
Social Worker	5	8.6
Family Support Worker	2	3.4

This quantitative PCN information provided a skeleton for the overall structure of the PCN as shown in Figure 18. The average of seven actors only included those with whom participants had direct contact in relation to their care (i.e. excluding administrative personnel, supportive staff or intermediaries) and was not limited to one person (i.e. actors in SNA were approached as people and/or services). Where possible, data were gathered (particularly during the interviews) on how many 'different individuals' this set of 'actors' involved.

Second theme framework for qualitative analysis: structure of the PCN

As mentioned, one actor indicated in the questionnaire and thus the PCN, did not necessarily mean a single person. The interviews revealed that, particularly for indicated IC actors in the questionnaire, one group of actors could involve several people. For example, involvement of 'family' as an IC actor in the questionnaire was elaborated upon in the interview by providing specifications of aunts, sisters, brothers, cousins, etc., that were part of this broader 'IC actor'. As such, apart from reflecting the importance of the domains of care from the questionnaire, the interviews allowed a more accurate image, e.g. by showing the complexity and

nuances surrounding the IC network. In other words, the questionnaire inevitably limited responses (i.e. family, partner, friends and neighbours), but the interviews allowed for the identification of subcategories. For example, all interviewees (n=7) made a distinction between the wider family and immediate relatives and/or partner.

"Friends and family can be good, but they don't really understand […] don't really understand as much as my children and partner. They wouldn't understand that every half an hour or forty-five minutes you have got no choice but you need to stop for a rest […]. All they can see is the outside of you and the outside of you looks completely one hundred percent […] they don't realise that you get problems with you know your blockages, you get; you have got to be very, very careful." (pp7)

In addition, those (n=2/7) who lived further away from their immediate family and/or did not have certain people within that group (e.g. partner), tended to elaborate in greater detail on the structure of those living around them (i.e. neighbours). Interviewees who did not have their family nearby showed higher reliance on neighbours, friends and even people in the wider community.

"[…] I have an elder sister who lives in Manchester so all of her family are up that way […] So no I count myself really very lucky, especially with my neighbours [...]. I've got brilliant neighbours who are extremely good, especially the chappie next door that way […] he is extremely good, he'll come in and change my light bulbs and things like that for me and other little odd job that I need doing that I can't do. And I even sometimes have to run next door with a jar and say 'Can you open that for me please?' Because even with the gadget, the gadget won't open the jar." (pp1)

"PP (partner): Yeah they (friends) were particularly there before I came along didn't they?

PP: Yes they (friends) drove me everywhere when I was struggling with my knee. And yeah neighbours help…" (pp2)

The study's mixed method approach resulted in the interviewees' post-interview PCN maps allowing for more detail than their pre-interview PCN map. For example, the PCN on the right-hand side in Figure 19 shows the added actors (blue ties) mentioned during the interview.

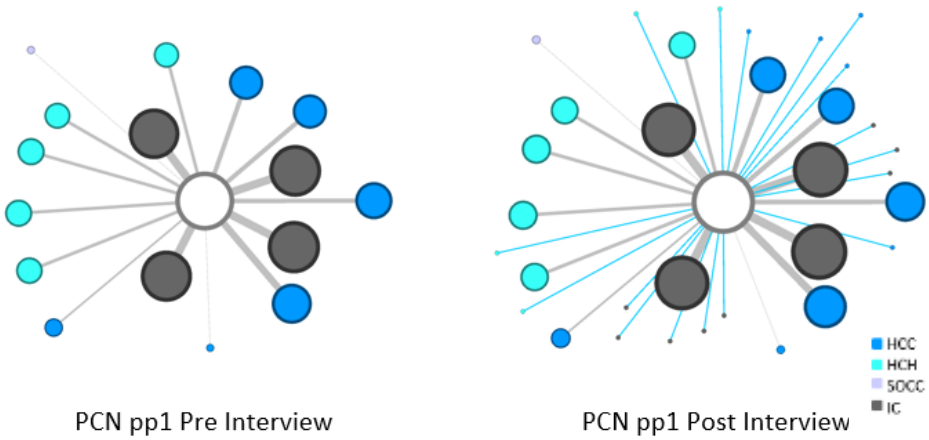


Figure 19: Pre and post interview PCN

4.3.2.2 Which care domains encompass the PCN?

Descriptive statistics and SNA

Four domains of care (SOCC, HCC, HCH and IC) were predefined for inquiry in the questionnaire (see section 4.2.1). Figure 20 displays the structure of the PCN according to these domains of care. The different domains of care were allocated different colours to provide a domain sensitive graph. The average amount of actors indicated as important per domain was slightly higher for HCC (four) than the other domains (SOCC=one, HCH=three and IC=two). The domain specific averages relating to contact did not show much internal variation; generally,

participants indicated three HCC, HCH and IC actors they were in contact with and one in the domain of SOCC.

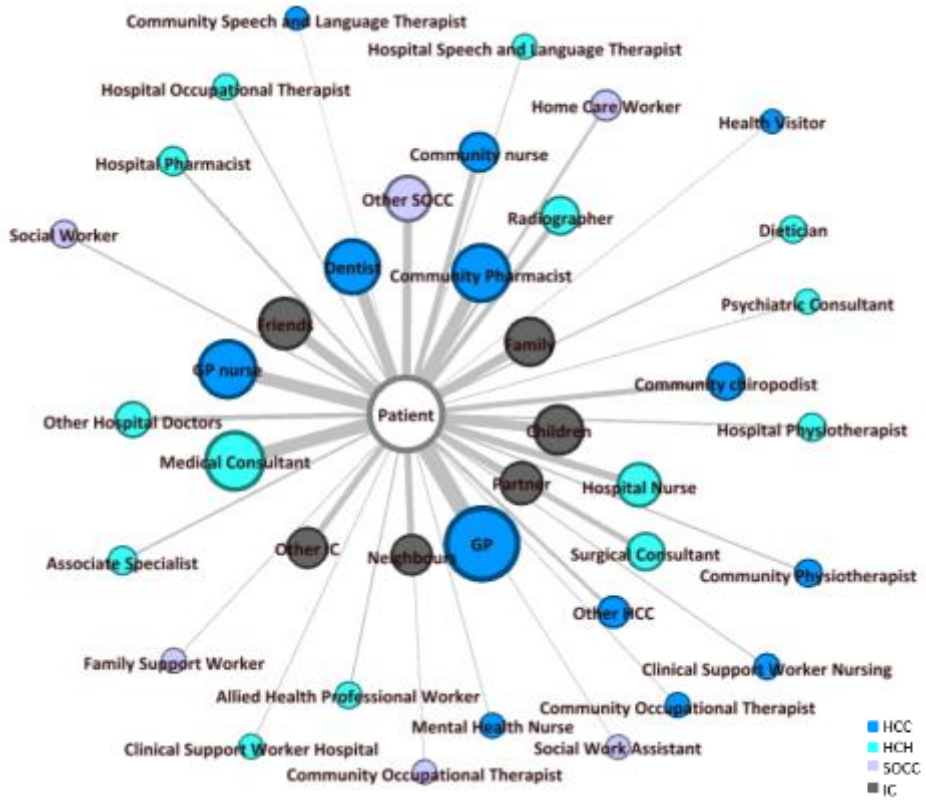


Figure 20: Actors reported to be involved in the PCN per domain

Both the interview and questionnaire data suggested a smaller involvement of formal social care than any other type of care (i.e. hospital, primary care, informal and third sector care). Less than a third (30.6%, n=19/62) of the participants indicated one or more SOCC actors to be involved in their PCN. Over double this amount (67.7%, n=42/62) was reported for HCC actors and 51.3% (n=32/62) indicated the involvement of HCH and IC actors. For the majority of social care, patients indicated the answer option 'other'. Closer investigation of the clarifications of 'other' and analysis of the interview data, revealed that these were frequently IC actors.

Third theme framework for qualitative analysis: roles and responsibilities in the PCN

In addition to the numerical data provided by the questionnaire, the description of the PCN during the interviews enabled an in-depth understanding of individual 'networks'. In contrast to the questionnaire, the interviews did not predefine domains (SOCC, HCC, HCH and IC) for inquiry. As such, the groups of care emerged from the interview data related to how patients perceived and classified actors based on the type or levels of support perceived as provided. When describing the PCN during the interviews, participants tended to distinguish *three levels of support*: support provided on a **day-to-day** basis, frequently used services/providers for **monitoring and follow-up**, and **'exceptional' care** delivered by professionals.

> *"[…] the people who I sort of had access to, to sort of help me with my initial problems and then with my problems […] after the actual initial treatment because I, I've got a problem that I will always have. So it's good that there is a care network in place. There's; there are local charities, there's the stoma nurses, there's the local Ileostomy association. I go to see a consultant once a year at the hospital so to me that is the…my care network, as well as friends and family." (pp7)*

The interviews revealed that daily continuous support was mainly provided by informal carers, whereas follow-up activities and expert care were situated respectively on the level of primary and secondary care.

> *"[…] So you've a group of more exceptional people to access than you have informal care givers who are there on a day to day basis. And then you've those that you basically access on a frequent basis to keep in check with the conditions that you have." (pp5)*

Integration of the data further led to the identification of *five main categories of actors* in the PCN (Figure 21): the patient him/herself (a), the GP practice (b), the informal network (c), the experts involved depending on the type of LTCs patients were diagnosed with (d) and additional services used as required (e).

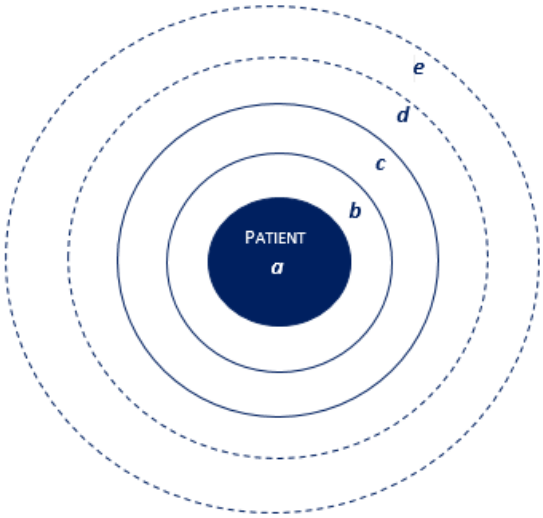


Figure 21: Five main categories of actors identified in the PCN

The first three (a-c) were found to be the 'core' of the PCN, remaining relatively stable across patients' time living with LTCs. The presence and amount of experts (d) and additional services (e) however were more subject to change. Reasons for this can be found in section 4.3.4 where the results of the third theme of the framework for qualitative analysis are discussed.

"[…] It's the same system being used, whatever, whatever illness I've had, it's the same system I've used except it's been different consultants." (pp2)

"[…] I think I have found the same sort of thing no matter how you know because well I first started with my arthritis, well I was still working you know. So and I still found that the system here with the hospital care and all that was still the same you know. And even G.P.'s and friends and neighbours and things although my parents were still alive then you know and I actually lived with

them […] yes, there's obviously another specialist I have since they discovered it, because I mean I have to go and have my heart check and see that I'm alright." (pp1)

4.3.3 Changes in structure of the PCN

4.3.3.1 Does the PCN structure differ according to the number of LTCs?

Descriptive statistics and SNA

A strong positive relationship was found between the number of LTCs and the amount of actors important to ($r=0.60$, $p<0.001$) or in contact with the participant ($r=0.52$, $p=0.001$) in the PCN. The higher the number of LTCs one was diagnosed with, the more actors were involved (Figure 22). Around 22% of the variation in the amount of important actors was explained by the number of LTCs. In general, for each additional LTC diagnosis, one more actor became important ($F=11.701$, $p=0.002$, $b=1.253$, $t=3.421$, std. error=0.366). Similar results were seen for the amount of actors in contact with ($F=13.004$, $p=0.001$, $b=1.462$, $t=3.606$, std. error = 0.405); with each additional LTC, the patient was in contact with one more actor. Nearly a quarter (24.5%) of the variation in contact was explained by the number of LTCs.

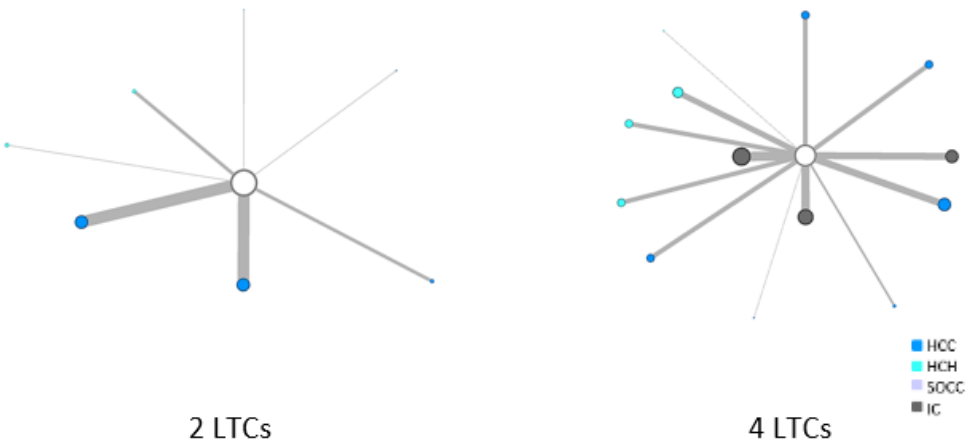


Figure 22: PCN from participant with 2 LTCs and 4 LTCs

On a domain specific level, strong positive relationships were found for the number of LTCs participants were diagnosed with and the number of HCH (r=0.63, p<0.001) and HCC (r=0.60, p<0.001) actors indicated to be important. Over a third (37.6%) of the variance in the amount of HCC actors found important (F=20.906, p=0.001, b=0.936, t=4.572, std. error=0.205) and one fourth of that regarding contact (F=12.991, p=0.001, b=0.663, t=3.604 and std. error = 0.184) was explained by the number of LTCs. Weaker positive relationships were seen for the number of LTCs and the number of actors important in HCC (r=0.38, p=0.019) and SOCC (r=0.34, p=0.039). In addition, a significant, but weak, relationship was found between the number of LTCs and the amount of alters in contact with in IC (r=0.36, p=0.029).

4.3.3.2 Does the PCN structure differ according to age and sex?

Descriptive statistics and SNA

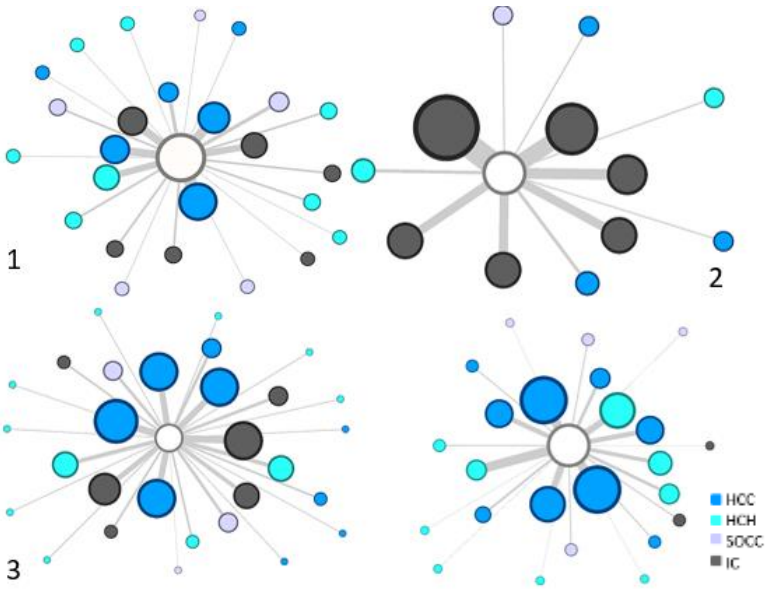
Overall, there were no significant relationships between participants' age or sex and the amount of services involved (important or contact) in the PCN. On a domain specific level, participants' age did show positive, albeit weak, relationships with the number of HCC (r=0.35, p=0.007) and SOCC (r=0.30, p=0.015) services participants were in contact with.

4.3.4 Reason for involvement of actors in the PCN

Descriptive statistics and SNA

Alongside the importance and contact with actors, data revealed information about the 'main reasons' for contact (Figure 23). Participants reported to mainly receive emotional support (32.3%, n=20/62) from informal actors. The main type of support provided by HCH and HCC actors was care (respectively 22.6%, n=14/62

and 29%, n=18/62). Practical support was the main type of support indicated among SOCC actors (11.3%, n=7/62).



(1. Information and Advice; 2. Emotional Support; 3. Practical support; 4. Care)

Figure 23: Differences in PCN structure according to type of support

The overall PCNs in relation to LTC, short term problems related to LTC and short term problems for formal care actors are shown respectively in Figures 24-26. The majority of contacts with HCH (87.14%) and SOCC (86.33%) actors were related to the LTCs participants were diagnosed with. This was the same for nearly two third of the encounters with HCC (66.3%).

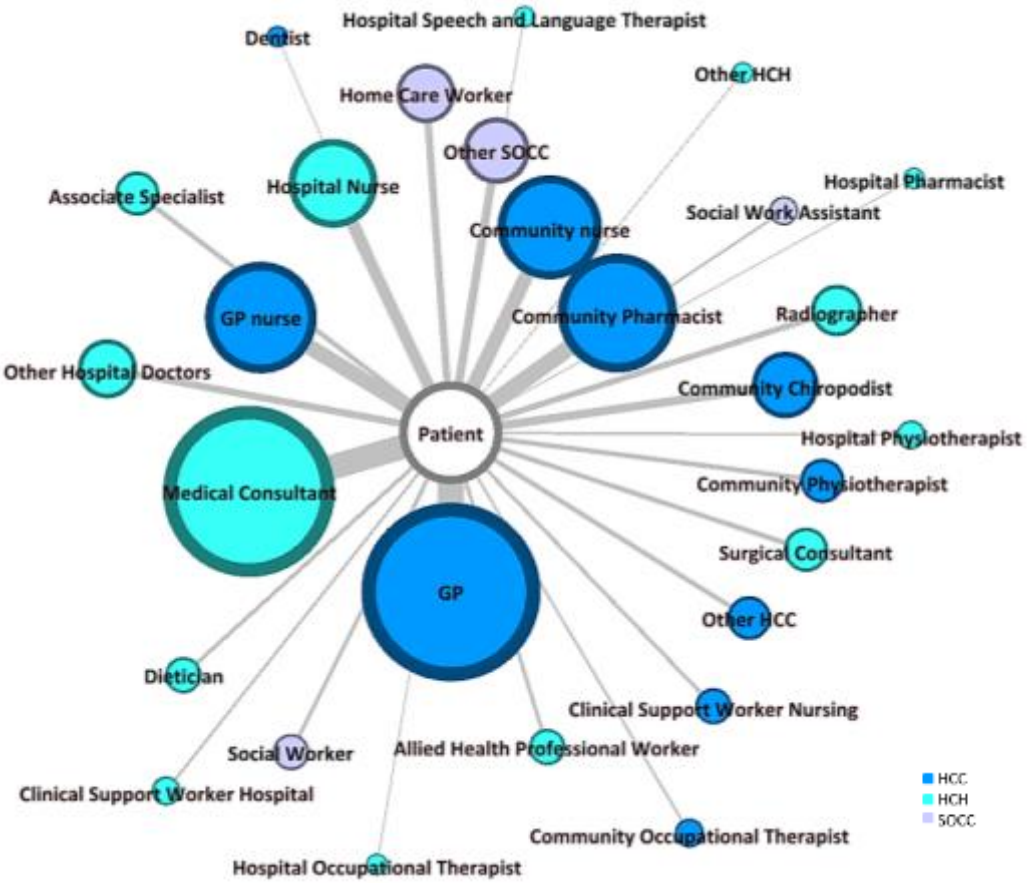


Figure 24: Actors in PCN approached for LTC

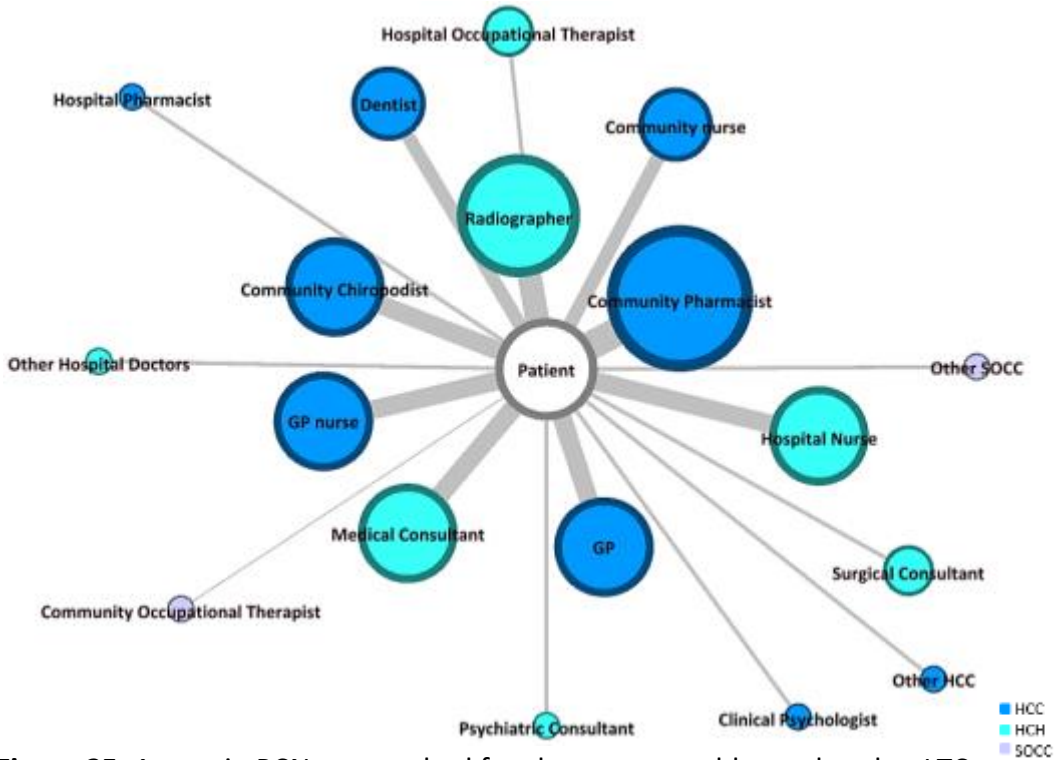


Figure 25: Actors in PCN approached for short term problem related to LTC

Out of the three formal domains of care, HCC seemed the most (35.8%) used for short term problems compared to SOCC (13%) and HCH (12.86%).

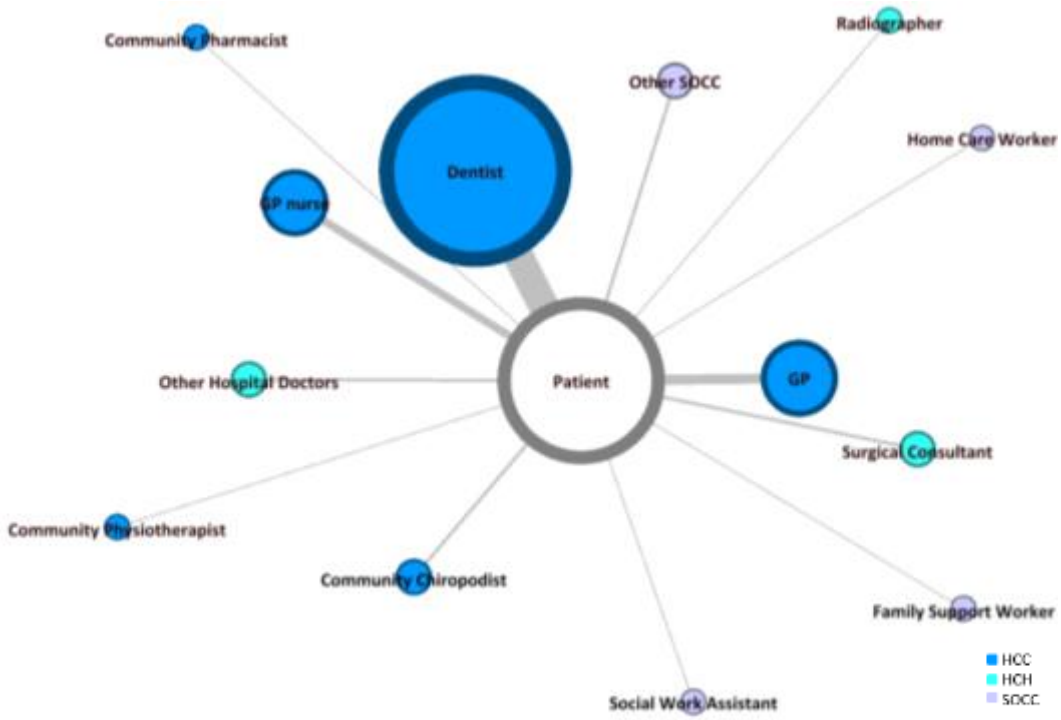


Figure 26: Actors in PCN approached for short term problem

The interview data provided more detailed information on the reasons for involvement of actors in the PCN. Two themes related to this subsidiary question: the third theme (roles and responsibilities in the PCN) and the fourth theme (first point of contact). Both are discussed in detail below.

Third theme framework for qualitative analysis: roles and responsibilities in the PCN

From the interviews, the five main categories of actors (Figure 21, p.175) identified in the structure of the PCN, patient (a); GP practice (b); informal network (c); experts (d) and additional services (e) were investigated in terms of their roles and responsibilities.

a) Patient: Self-care, disease management and assertive communicator

The interviews showed a strong sense of awareness among participants in terms of their own responsibility as a patient. Interviewees (n=7) pointed out their own

actions in contribution to their health (physically) and wellbeing (mentally). From the interviews, two distinct types of behaviour emerged: actions undertaken to remain as healthy as possible (self-care) and measures taken to control and manage one's LTCs (disease management).

The two frequently mentioned **health promoting actions** were healthy eating and physical activity. The latter could take different forms, depending on the age and level of current and past physical fitness. Participants mentioned daily activities such as gardening and household work as well as exercise (e.g. walking, cycling and swimming).

> *"It's all very easy exercises it sorts of fits in. I think I'm probably one of the fittest of the lot of them. And I walk the little fellow (dog) out regularly so we go for walks and that and euhm yeah I do exercise, I do my own house work, I sort of wander around, do my own gardening." (pp3)*

Another element that emerged (n=3/7), was the need to find activities that were possible or adjustable to the interviewees' LTCs. One participant in particular found this a struggle.

> *"[…] go to the gym at least three times a week. And do euhm, we do aqua aerobics as that is all I can do, I can only do things in the pool. Because, because anything else is not good for arthritis. So yes, that's mainly what we do to stay healthy and try to eat healthy." (pp2)*

> *"PP: Yeah, I was hoping at the time to get a referral to see a physio specialist, exercise specialist those kinds of things really […] No basically I am on my own really sort of thing […] So yeah; so yeah I try and do as yeah.*
> *INT: So you are basically trying to solve it what so…*
> *PP: As much as possible.*
> *INT: Meet that need yourself?*

PP: As much as possible yeah." (pp7)

Whereas physical activity and healthy eating were addressed by all (n=7), the importance of sleep and/or rest and moderate alcohol consumption were only mentioned by two out of seven interviewees.

"I try to eat well and sensibly. I try to get as much sleep as I feel I need, because I am retired and if I am tired in the daytime, I actually go and lie down and sleep more in the daytime. Sometimes morning and afternoons, so you know when I am feeling a bit like this like a growing puppy really. But and I you know I am very moderate with my drinking. I do some physical activity […]" (pp5)

Two out of the seven patients that took part in the interviews, disclosed a mental health issue (i.e. depression). However, all interviewees spontaneously stated the importance of self-care in terms of mental health (wellbeing) sometimes (n=2/7) even if that meant potentially going over their physical limit.

"[…] my responsibility is obviously to keep as healthy as possible, mentally and physically." (pp6)

"All these things to do that are active and people say to me. "You have got bad hips why the hell do you go on diving boards?" and I go "You know actually I moderate what I do on the diving boards." But you know for me it just seems a tossup between running these risks that come with sailing or with diving or the gym or dying of depression. And I don't want to die of depression." (pp5)

Self-care behaviour also included seeking help from the actors in the PCN to, for example, prevent worsening of the situation.

"Euhm a care network to me means euhm organisations of various skills but euhm that people can call on when they are sick, ill or euhm in need… Euhm,

to support them generally such that they don't have to divert to such things as the hospital and alike." (pp6)

In relation to **disease management** interviewees emphasised their responsibility in terms of medication adherence, attendance of appointments and daily monitoring of their conditions.

"My responsibility is obviously to keep as healthy as possible, mentally and physically… euhm I think that's a main responsibility. Another one is obviously euhm attend to anything with the doctor or nurse or medical health dentist etc. before it becomes a critical issue sooner rather than later in other words." (pp6)

Dependent on the LTCs participants were diagnosed with, disease management and self-care sometimes overlapped and at other times challenged one another.

"It has been a bit of a struggle trying to keep the weight off because everything what is bad for you, you can eat nearly. You can eat cake, you can eat biscuits, and you can eat chips. But everything like what you would have eaten before like salads, fresh fruit you know, fresh vegetables most of those things unfortunately you can't eat anymore […]" (pp7)

Based on experience, participants developed their own personal ways to practically manage their LTCs and the people involved in their PCN. The use of diaries to keep track of appointments was present in all interviewees (n=7). In addition, some (n=2/7) kept a log of the reason and outcome of appointments as well as their medication.

"Diary and yeah I've various things on my computer, like I have a medication list knowing what the medication is for […] I have, every time I go to the GP or go to the doctor or go to the to the hospital, I've a list of every time I've been. Because often when you go they'll say to you 'and when did you last do this?'

and I was thinking I'll never going to remember so I actually got a log, I started it in 2008, every appointment I've ever been to." (pp2)

"Well, I take my medication well I'm actually, I'm changing over my medication myself to, I've made arrangements to have my medications in a dosage boxes?" (pp4)

Occasionally (n=2/7) patients mentioned that they felt as if they were not given the tools to keep track of their health and/or care.

"You know all this business with that they said they gonna let, you can access your medical record? But you can't!" (pp4)

The third main activity that arose across interviews was the patients' need to be **assertive, determined and proactive**. As this was also found a major factor influencing PCN navigation this is discussed in more depth in Chapter Five (section 5.3.2).

b) GP Practice: Gatekeeper and general monitor

GP practices were reported by participants, (both in the interviews and questionnaires), to hold a central position in their PCNs. The interviews revealed that this central position was the result of and strengthened by two main roles: the GPs 'gatekeepers' role and their function as a general monitor of patients' health.

All interviewees discussed the process of **referral** through GP practices, and the GP in particular. **Access** to different (health and social care) services in primary, secondary and sometimes even third sector care was gained through the GP. Exceptions to this were patients (partly) choosing to take the route of private care (n=2/7), but even then the GP was often asked for information of services that could be approached.

"With the chest and everything I just have go to the doctor and she says oh yes you better go to the hospital." (pp1)

"Yes, everything has to go through the GP, well not the dentist, but everything else goes through the GP surgery." (pp2)

"I got in from our local general practitioner, a list of companies offering private auxiliary care help." (pp6)

In addition to the referral, the GP practice was also the place patients went to when they wanted a re-referral.

"[…] The first referrals were to E.N.T. consultant. And so I had one referral and I really wasn't happy with that consultation so I asked for a re-referral to a different consultant in E.N.T. which then happened. And that was much better. That consultant then referred me for the M.R.I." (pp5)

Apart from being the Actor in charge of referral, providing access to other parts in the care system, the GP practice was also seen as the place to **monitor patients' general health**. General check-ups were often scheduled ahead (e.g. every six months) to keep an eye on patients' LTCs such as diabetes. Disease specific follow-up (if needed) did however not fall under the responsibility of the GP practice (see roles and responsibilities of experts) according to the study participants.

"PP: Nearly 40 years ago and I was still working… I don't think I saw anybody just… no I can't remember seeing anybody just the GP, oh and the nurse who was in that GP practice […]
INT: (laughs) So, it's mainly your GP that…
PP: That does it. Yes, once a year with him and once a year, alternate six months is the nurse.
INT: OK, what about managing the hypertension for example?

PP: No, just the GP, the same for thyroid and cholesterol and everything, just the GP." (pp3)

"[…] For example with the asthma I had a lot of problem with that many years ago and I was seeing my consultant on a regular basis, but that was resolved so I'm now just managing it myself and because the NHS asks you once a year to see the nurse at the practice just to make sure that you're OK… Same with the diabetes." (pp2)

c) Informal network: Day-to-day support

Drawing on the interview analysis, the informal network was reported to be the main source for patients' day-to-day support. Depending on its structure (i.e. solely family and friends or also including the wider community), roles and responsibilities of informal actors were shared differently and divided among those involved.

"PP: […] We are lucky at our bowls club because we have a restaurant and we have a bar, you know so it is very convenient. And this to me is that sort of care in the community is where people look out for each other you know?
INT: Yes
PP: Even a casual greeting of, 'are you alright today?' You know it means that they're asking you if you are alright and is there anything that you need... or can I help in any way you know?" (pp1)

Entailing various things, day-to-day support mainly involved **practical** and emotional support. Practical support, such as transportation, was often mentioned (n=5/7) when discussing the importance of family and friends.

"There is, one time my pressure blew and they were all away, my family and my friends were away, I was sort of stuck that little bit, but more friends gave me their telephone number so I could call more people, in fact one waited for

me till I come out of the GP. So, I felt, right, you know, now I've got more that I can approach if need to be…" (pp3)

"Sometimes use a friend of church for attending the doctor at surgery when I haven't been able to drive myself […] I have an address book and I try not to bother the people with surnames starting with 'A' too frequently (laughs). Which today we will stick the pin in the 'W's' or the 'S's' or the 'C's' or... you know." (pp6)

Secondly, friends (and sometimes the wider informal network) were a source of **information**. Information and advice was in particular sought in relation to 'connections' friends might have access to and the patient (currently) did not.

"That (contacting a healer) was at the recommendation of a friend." (pp5)

"I made inquiries with friends and things, did they know one (chiropodist)? And this is how I got to know this one. You know, it was just through an old friend." (pp3)

It was noted that for advice on medical issues, participants were more inclined to rely on professionals than on informal actors.

"I don't wanna bother them with things they can't necessarily answer. I mean if effectively it's a medical problem you need to see a doctor, don't you? You don't ask them… well apart from my friend whose daughter is a doctor so that sort of helps." (pp2)

Thirdly, family and friends played an important role in **emotionally supporting** patients by for example being an outlet to talk through acute episodes in LTCs or take their mind of the situation.

"Well I talk a lot to my brother about my feed… my fading health. So he knows, I don't tell my father because I don't want him to know. My partner Michelle,

I tell her and she's really caring but you know for instance with the neck pain […] she's very considerate when she sees that I am in obvious pain. She says 'Oh sit down and shut up and stop there you are trying to do too much' and she always offers her advice […]." (pp5)

"If you know; if you like sort of thing. Okay they haven't got a title as such, but yeah without yeah, without partner and children yeah I don't know if I would have actually got through the mental rather than the physical sort of thing." (pp7)

Lastly, immediate family and partners were frequently mentioned to provide **informal (social) care**. Informal actors often were the ones mentioned under the category 'other' SOCC.

"Euhm, feeds me, I think the other aspect is that euh general hygiene of euh washing, ironing clothes and things like that […] and euh, I mean general, generally helps me and I imagine she helps me more than I help her." (pp6)

d) Experts: Condition specific needs

The type(s) of experts involved was dictated by the type of LTCs patients were diagnosed with. The role patients perceived experts to have however largely remained the same regardless of their specialism. According to the interviewees, specialists at the hospital were a source of **disease specific** testing/monitoring and information.

"Now when they stuck, you know they don't come out. You are in agony and you have to go to the hospital, you have to have drips, you have to have morphine so, so yeah." (pp7)

"I have to go and have my heart check and see that I'm alright. And I spent a lot of time in the hospital I know my way around there as well. You know

(laughs) because I have to go to the heart clinic, the chest clinic, the blood place and then anything else. I mean I am forever... X-Ray, I mean you know so yes I know the hospital quite well." (pp1)

e) Third sector, private care and organisations

The fourth and final group that arose from the data was care provided by organisations, patient groups, et cetera. Some of these required payment from the patient, others were offered on a charity basis. Third sector organisations generally comprises services that were used as **'substitutes' to NHS care** or ways to support needs that were not addressed elsewhere. As such, this group reflected a personalised addition to the PCN of patients with multimorbidity in accordance to their needs. Services included gardening and companies specialised in transportation for disabled patients.

"The Spinal Injuries Association. Whereby there as an association you can got to them for information or get a periodical from them two or three times a year which contains advertisements from companies that are offering either equipment or services for the benefit of disabled people." (pp6)

"The ileostomy association is great because it is an organisation that you pay £15 a year for and it is there whenever you need it." (pp7)

Apart from substituting NHS care, private care was also sought by patients that wanted **timely advice or care**.

"And sometimes I, the person that I've seen, there's a private physio, he's, if I want it done quickly." (pp2)

"He (chiropodist) comes, he's a private one, so he comes because they discharged me from, at one point they had a diabetes one but now, unless

there is something wrong, they don't see you. So, I found this one, who's an euhm private one and actually he's good, he's good." (pp3)

Fourth theme framework for qualitative analysis: first point of contact

Another theme that revealed information on the reasons for involvement in the PCN of older people with multimorbidity was that of 'first point of contact'. All (n=7) but one interviewee had an idea of who their **first point of contact** would be when feeling unwell. For the majority of issues this was the GP, unless it was (disease) specific.

"INT: So, if it's OK with you, we'll have a look at how that contact goes. For instance, your GP…
PP: That's the first port of call yeah." (pp2)

"INT: When you decide that you need health or social care from a professional, where do you go? How do you know where to go?
PP: I probably have a word with the GP I think." (pp3)

In case participants were facing a disease specific issue, they mentioned approaching the consultant, expert services or online patient groups (e.g. Facebook and fora).

"I've got a number; I've got a little card with a telephone number on […] with the haematology actually because when your red cell count is getting very low you sort of feel, you sort of know." (pp1)

"[…] I mean I was desperate, even on Facebook, one day I actually wrote and have wrote now for about two or three months. I have had this problem sort of thing, yeah and going out of my mind with it can anybody...? And yeah, people who I had never even heard of before came round and see me because yeah that's how... […] It's like today if you got home and you had a problem

the first thing you do is – aye up I've got pain to my left hand side anybody else got help. And within minutes there will be a list that big, aye up we think it's this or yeah definite; if everybody says aye up go see your G.P. is this you do you know what I mean? But lots of the time they will say 'no make sure you drink'." (pp7)

Only one interviewee mentioned a one-off involvement of the NHS 111 service, instead of the GP, when she was unsure where to go next in the care system. The GP was also passed by when patients were in need of immediate urgent care (e.g. ambulance service).

"[…] it was yes it was over a year ago now, when I got up one morning and I thought my day had come to go and meet my maker because I could not breathe and... and I knew that I couldn't even pick the phone up. Well I picked to ring the ambulance to make sense to them, I picked it up and just pressed my neighbours number across the road and I think she was over here before I had even put the phone down you know? So she rang the; you know. I was just sat here gasping for breath, and the ambulance on that occasion they were brilliant, they were here in no time you know. And I was on the oxygen and all the lot. Away went on the blue lights and yes so they were brilliant in A&E and they were brilliant in the wards […]" (pp1)

4.3.5 Changes in the reason for involvement of actors in the PCN

4.3.5.1 Does the reason for involvement differ according to age and sex?

Analysis pointed out a relationship between **age** and some of the types of support received from HCH and HCC actors. Older participants (>75 years) were almost five times more likely to receive information and advice as main type of support from HCC actors (p=0.023, Exp(B)=4.641) than younger participants (55-75 years old). They were also nearly seven times more likely to receive care as the main type of

support from these actors (p=0.002, Exp(B)=6.933) than younger participants. Compared to younger participants, older respondents were seven times more likely to receive information and advice as main type of support from HCH actors (p=0.025, Exp(B)=6.806). For all other domains, no significant differences were found between age and the receipt of information and advice, practical support, emotional support or care. Whilst bearing in mind the skewed sex ratio in the study (see section 4.3.1.1), no significant differences in the reasons for involvement were seen according to sex of the participant.

4.3.5.2 Does the reason for involvement differ according number of LTCs?

The **number of LTCs** was found to be a significant predictor for practical support received from informal actors. Those with four or more LTCs were four times more likely to receive practical support as main type of support from IC actors than those having two or three LTCs (p=0.041, Exp(B)=4.250).

4.3.6 Way of involvement of actors in the PCN

The majority of interactions within the PCN happened through face-to-face contact (Table 13). However, despite the instructions to 'choose one' option to establish the main way of contact, paper questionnaire responses frequently indicated more than one option. Especially within the informal care network (17.7%) and with HCC actors (9.6%) combinations of methods were indicated. These usually involved face-to-face contact in combination with either electronic or telephone (including Skype) contact. Owing to the small number of participants who only indicated one option as the main way of contact, significant differences between the groups could not be established.

Table 13: Main way of contact in the PCN

MAIN WAY OF CONTACT (N=62)				
	HCC	HCH	SOCC	IC
Electronic	8.1% (n=5)	1.6% (n=1)	1.6% (n=1)	3.2% (n=2)
Telephone	12.9% (n=8)	1.6% (n=1)	8.1% (n=5)	22.6% (n=14)
Face to face	54.8% (n=34)	45.2% (n=28)	16.1% (n=10)	37.1% (n=23)

4.4 Conclusion

Whilst this thesis did not intend to look at 'social networks' as such, the principles underlying SNA enabled the exploration and identification of actors that patients with multimorbidity perceived to be important and relevant in their care. Numerous applications of SNA exist within and beyond social sciences, including anthropology, communication science, organisational science, economics, geography and sociology (Scott and Carrington, 2011).

This was the first time SNA was used to visualise the PCN of patients with multimorbidity. In combination with framework analysis, both PCN structure and actors' roles were explored. The framework for analysis of the qualitative data was based on the topic guide (section 2.6.1.2), the emerging themes from the data and the underpinning Patient-Centred-Design framework (section 2.4.2). Initially the major components in the data were identified. These were then broken down in

detail to gain understanding of the nature of these components and eventually inferences were made about the data (Lazar et al., 2010) and in connection with the quantitative results.

The analysis of the quantitative data focussed on gaining this structural view of the PCN. It looked for the people involved and reasons for involvement rather than a focus on the frequency of contact as such. The latter had been previously explored (e.g. Baird et al., 2016). However, the results of this chapter have ensured completion of the image of care contact in older people with multimorbidity; answering the research questions around **'who'** is involved in the PCN of older people with multimorbidity and **'why'**?

As such, this chapter contributed to the second objective of the study by analysing and visualising the structures of and interactions in the personal care network (PCN) of older people with multimorbidity and gaining an understanding of their experiences of navigating their PCNs.

The following subsidiary questions were answered in this chapter:

a) Which actors are involved in the PCN of older people with multimorbidity and from which care domain (SOCC, HCC, HCH, IC)?
b) Does this structure of the PCN differ according to the number of LTCs, age, sex?
c) Why are these actors present in the PCN of older people with multimorbidity?
d) Does this reason for involvement differ according to the number of LTCs, age, sex?
e) How are actors involved in the PCN of older people with multimorbidity?

The first three questions were addressed by both quantitative and qualitative data (themes two to four), the latter two relied solely on quantitative data. This chapter visualised the PCN of older people with multimorbidity according to different care domains and revealed that on average, seven actors are involved in the care for older people with multimorbidity. The data further reflected that the structure of the PCN can differ according to the amount of LTCs an individual is diagnosed with (i.e. the more LTCs, the more complex the PCN becomes). Finally, it discussed that different types of support might be sought from the PCN depending on the age of the individual diagnosed with multimorbidity. The roles and responsibilities held by the actors in the PCN and the wider structure of the PCN were also explored by the qualitative data (themes one to four).

Building on patients' navigation experience and interaction in the PCN, the Identification of elements for improvement in care navigation and the delivery of design requirements for the development of an ICT tool to support care navigation (objective three of the study) are addressed in the next chapter. Here, data on the care navigation experience, including barriers and facilitators as well as patients' requirements for support in this task are bought together. Chapter Five displays the qualitative data gathered in relation to themes five, six and seven of the framework for analysis.

5

Communicating Design Requirements

In this chapter, the data were integrated, interpreted and communicated in a manner consistent with the interdisciplinary field of Human Computer Interaction (HCI). Such integration was a necessary part of mixed method research (MMR). It also formed the foundation of the tangible output of this study: personas of older people with multimorbidity.

A brief background to user-centred design (UCD) and designing for older people is discussed first. This is followed by details on the process involved to develop personas. In the third section, results on PCN navigation experience are presented. After highlighting barriers and facilitators of PCN navigation, the identified user needs are summarised. Finally, there is a discussion on the personas derived from this study and their theoretical background for development. These outline what PCN navigation looks like for older people with multimorbidity and highlight design requirements of a digital navigation support tool.

5.1 Designing for older people

5.1.1 Information and communication technologies

As much as the demographics in our society have changed, so have the ways in which its members use technology. Information and Communication Technologies (ICT) are becoming a necessary part of many people's lives. Along with work-related use, ICT is increasingly used to help manage lifestyles, communicate with one's social network, fill leisure time and provide entertainment (Goodman-Deane

et al., 2009). Whilst older people are seemingly slower in adopting these technologies than younger cohorts, they are a user group that could greatly benefit from what ICT has to offer (Goodman-Deane et al., 2008; Goodman-Deane et al., 2009).

Technology is only useful if and when it can be used effectively by its target users (Goodman-Deane et al., 2008). This is no different when those target users are older people. If anything, this user group is a unique group within the HCI field. Research with a focus on ICT and older people is expanding (Khosravi and Chapanchi, 2016; Wagner et al., 2010), with a steady increase of publications between 1990 and 2008 (see Figure 27).

Early research in assistive technologies began over two decades ago (Khosravi and Ghapanchi, 2016). In the 1990s, the function and use of computers started to change. Their main function moved away from business applications (e.g. text processing and calculating) towards personal usage (e.g. a medium via which one could access the internet) (Wandke et al., 2012). Unlike traditional computing tasks, email communication and the supply of a wide range of information became increasingly interesting for people, including older adults (Wandke et al., 2012).

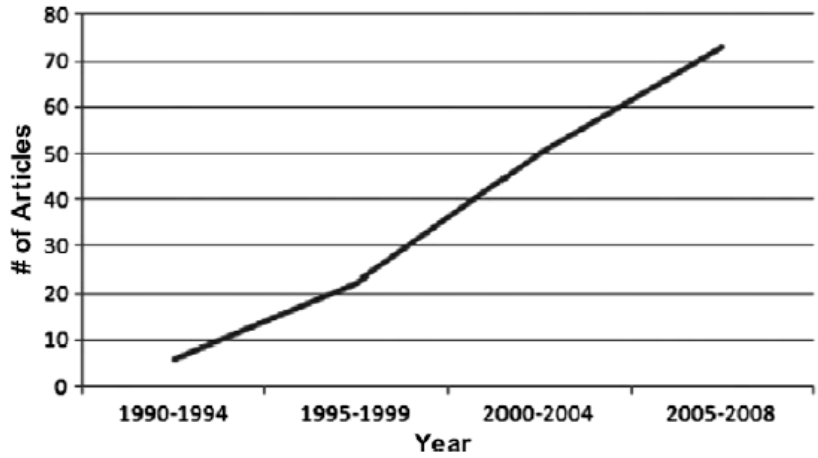


Figure 27: Articles on ICT and older people published by year (Wagner et al., 2010:871)

Over time, different disciplines became interested in this field of research. Figure 28, shows that the HCI field remained the 'driver' of research on ICT and older people, with a total of 56 studies published over eighteen years. The field of gerontology was, however, not far behind with a total of 40 studies published between 1990 and 2008 (Wagner et al., 2010).

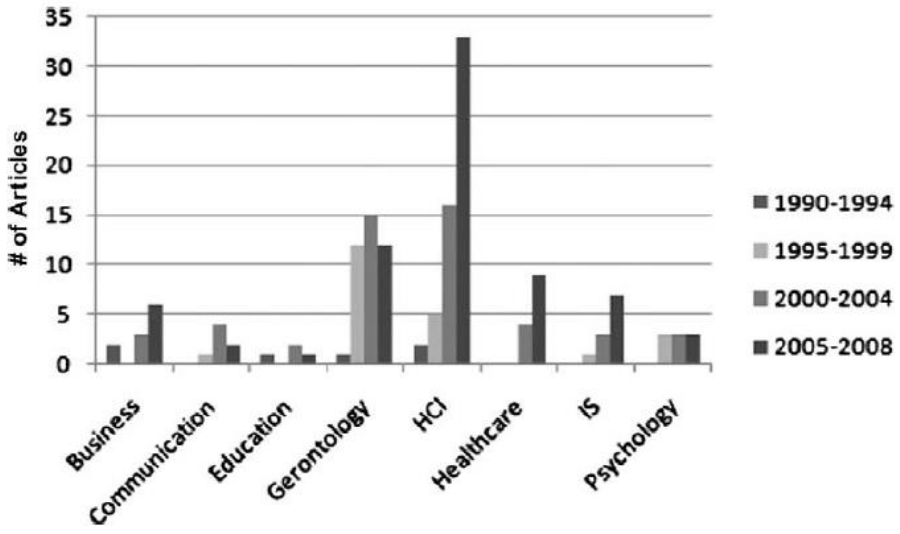


Figure 28: Publication trends by discipline (Wagner et al., 2010:872)

As the number of studies increased and the disciplines examining ICT for older people expanded, the concept of 'older people' started to vary. Older people are not a homogeneous group (Moser et al., 2012) and depending on the research focus, the term 'older people' can encompass different age groups. Research with a main focus on health can for instance refer to 'older people' when aged 85 and over. In the field of HCI on the other hand, people as young as 55 years or even 45 years, could be included when discussing the design of systems for 'older adults' (Wagner et al., 2010).

5.1.2 User-centred design and the user experience

Ensuring good design requires a dialogue with the end-user (Wright and McCarthy, 2010; Preece et al., 2015). Designers and developers need to have a clear understanding of: (1) what the potential end-users want the system to do for them; (2) how those end-users get their work done at present; and (3) whether the users will be able to understand and use the yet-to-be designed system that designers wish to develop and implement (Wright and McCarthy, 2010). More concretely, in this thesis, data were gathered on how older people with multimorbidity currently navigate their PCN (sections 5.3.1 and 5.3.2), what support they argue they would need from a digital navigation system (section 5.3.3) and which requirements needed to be fulfilled in order for them to be able to use that system (see section 5.3.4). To gain these insights, a user-centred design (UCD) process was adopted (also see Chapter Two, section 2.4). As such, the development of a potential support system or service was guided and shaped by what users (or indeed patients) understood and required. The user's experiences and needs became central to the process (Caddick and Cable, 2011), taking the view that:

"The user knows best and is the only guide to the designer; the designer's role is to translate the users' needs and goals into a design solution" (Saffer, 2010, cited in Preece et al., 2015:322).

In UCD, the researcher and designer often have different but interdependent roles. The researcher becomes the interface between the user and the designer by gathering data, analysing the information and providing design criteria. The designer then interprets these criteria (e.g. by sketching) and focusses on their development (Sanders, 2002). Sanders (2002) identified a partnership between 'designer' and 'researcher'. However, the group of experts that should be included in the design or development team should involve a range of different and relevant disciplines (Preece et al., 2015), particularly when designing for older people (Wagner et al., 2010) (also see section 5.1.4). This thesis gathered user requirements (see section 5.3) and provided concrete documents (see personas in section 5.4) to support communication amongst those individuals involved in the development of a digital navigation support system.

In combination with UCD, the term 'experience-centred design' is often used. Experience-centred design focusses on people's lived and felt experience as they are living with technology. At the core of this design approach are people's values, emotions and perspectives. **Experience-centred** design *"is meant to encourage design thinking that focusses on the quality of the user experience rather than on the set of design methods to use"* (Preece et al., 2015:13).

According to Winograd (1996) cited in Wright and McCarthy (2010:27):

"Good design produces an object that works for people in a context of values and needs, to produce quality results and satisfying experience."

In other words:

"It is not enough that we build products that function, that are understandable and usable, we also need to build joy and excitement, pleasure and fun, and, yes, beauty to people's lives" (Norman, 2004, cited in Preece et al., 2015:13).

5.1.3 What makes older people unique in the HCI field

5.1.3.1 Impact of age related changes in cognition and physical ability

Older people differ from younger cohorts due to age-related changes in cognitive and physical abilities. Natural physical ageing patterns can affect motor function, visual acuity and coordination (Wagner et al., 2010). Natural cognitive age-related changes might involve a decreased attention span, decline in some of the memory function and changed spatial abilities (Petrie, 2001; Wandke et al., 2012). In addition, older people are frequently diagnosed with at least one LTC (see Chapter One). These conditions, as well as a combination of LTCs, further add to changes in physical and/or cognitive abilities. Age-related changes, whether they are brought on by LTCs or appear as a natural part of ageing, influence the way older people interact with ICT.

Designers working on ICT for older people have difficulties in finding concrete information (i.e. user perception, experience and requirements) on how to make technology accessible to a wider range of users (including older adults) (Petrie, 2001). Nevertheless, there is a growth in general information, recommendations and guidelines for the design of systems for older people. For example, a literature review by Luna-García et al. (2015) presented a set of design patterns for interactive social applications for older people. This set of patterns was reviewed by experts to evaluate their importance for older people. Guideline elements mentioned by Luna-García et al. (2015) related, for example, to the size of images, the colour of elements, simplicity of navigation, avoidance of scrollbars, slower interactions, et cetera. A similar study, literature review followed by empirical

evaluation, was done by Kurniawan and Zaphiris (2005) focussing on web design guidelines for older people. Kurniwan and Zaphiris (2005) pointed out the importance of search engines allowing for spelling errors, avoiding blue and green tones, adding spacing between lines, et cetera.

An overlap between the guidelines of Kurniwan and Zaphiris (2005) and Luna-García et al. (2015) was visible. However, overall such guidance would still seem to be limited (Petrie 2001). Petrie (2001) and Luna-García et al. (2015) report that although most guidelines provide general suggestions that relate to a range of disabilities or ageing, there is (at present) no information on how best to design for the (likely) changing and changed abilities of these individuals. Further, the information available for design teams does not necessarily increase their understanding of the 'problems' older users might encounter; nor is it clear whether these problems are addressed (Petrie, 2001).

The list of guidelines and recommendations for HCI and older people is invaluable and continuously increasing (Kurniwan and Zaphiris, 2005; Luna-García et al., 2015; Petrie, 2001). However, age related decline in perceptive, motor and cognitive skills continues to be a challenge in the development of interactive techniques for older people (Wandke et al., 2012). When designing for older people, particularly for those with mulitmorbidity, it also has to be born in mind that they are likely to have a different relationship with ICT when compared with a younger cohort (Ibid).

5.1.3.2 Different relationship with ICT

The difference between older and younger people in relation to HCI is more complex than their changes in physical and cognitive abilities. Whilst many older people are comfortable with using innovations such as microwaves, phones and the television, research has demonstrated that older individuals are not always aware of how ICT could support them (and thus often their attitudes towards ICT

are different). In discussing such differences (below), it should be noted that older people are not a homogenous group (Moser et al., 2012) and a somewhat broad use of the term 'older people' varies between, for example, 50 year olds and 80 year olds (Eisma et al., 2004).

Older people are usually less familiar with certain types of ICT (and thus their experiences in using ICT also differ) (Eisma et al., 2004). In addition, individuals may feel as if they are 'too old' for it (and so could feel alienated) (Ibid) and their interest in ICT tends to be lower than that in younger cohorts (Eisma et al., 2004). This mostly seems to be the case when the benefits have not been communicated clearly (Ibid). Older people also usually have lower levels of self-efficacy in terms of computer use (Wagner et al., 2010; Wandke et al., 2012).

Research examining the use of ICT by older people also demonstrated that when this group uses a computer, they have higher levels of negative emotional reactions when making an error. T, they were also found to make more errors, to be less efficient in browsing the internet, to seek more support when using the computer and to need more time to complete a task (Eisma et al., 2004; Marchibroda, 2015; Wagner et al., 2010). A further difference exists in the understanding of icons and symbols used in ICT. The older cohort is likely to be unfamiliar with the general ICT 'language'. The concepts, visual language and interface metaphors that are often used to make ICT easier to navigate for younger groups, can be an obstacle for older people (Eisma et al., 2004; Wagner et al., 2010). Older people might also believe that using the computer will require too much 'learning' (Eisma et al., 2004). Research has demonstrated differences in learning capabilities around ICT in older and younger people. However, one often needs to make a distinction between 'abilities' and 'motivation' (Wagner et al., 2010; Wandke et al., 2012). When older people are motivated and can perceive the benefits ICT use holds for them, they are able to 'learn' to use the relevant programme (Wagner et al., 2010; Wandke et al., 2012). It is not the age of the

individual that is the barrier to use; rather it is the perceived usefulness of an ICT application that strongly mediates the differences between younger and older age groups (Eisma et al., 2004).

5.1.3.3 Concerns among (older) people for the use of ICT for health and social care

Older people, as well as the wider population, could experience a set of barriers or concerns that limit acceptance of ICT for health and social care purposes. Costs of, for example, computers are a concern among older people (Czaja, 2015; Wagner et al., 2010) and patients might not have (easy) access to the internet and/or a computer (Czaja, 2015; Marchibroda, 2015). It should be noted that inequalities in access to computers and electronic devices still exist (also see Chapter One). However, Green and Rossall (2013) reported that this is likely to change in the future (i.e. devices becoming more available and affordable). Research has shown that further concerns around privacy, data management and data sharing can act as barriers to use technology (Czaja, 2015; Wachter, 2016). Systems must be safe and easy to use for people, including those with low levels of health literacy (Czaja, 2015; Marchibroda, 2015).

To overcome such challenges, a number of changes to existing ICT need to be made. Greater interoperability and interconnectivity of technology and devices is essential (Czaja, 2015; Wachter, 2016). Connections between personal and mobile devices, clinical and administrative health system software, medical devices and applications should be seamless (Marchibroda, 2015). To help, for example physicians, and to promote the use of systems, the reliability of the data will be an important factor as well as reimbursement policies around reading and analysing the data (Deering et al., 2013). These elements in particular influence the physicians' perception of the usefulness of the system. However, the opinion of other people (subjective norm) impacts people's likelihood to adopt certain

behaviour. In the use of telemonitoring equipment, older people value the opinions of their nurse and GP regarding the use of the devices (Vos et al., 2015). Effective promotion of technology for health and social care (Czaja, 2015) and increased awareness of the tools that are available (Marchibroda, 2015) can further aid adoption. It is essential that the real usability and benefit of the system for the individual is emphasised. Perceived usability and usefulness will influence the person's likelihood of accepting and adopting the system (Marchibroda, 2015; Wandke et al., 2012)

The importance of a 'positive' experience with technology is invaluable for the uptake of ICT among older people (Wagner et al., 2010). A positive interaction with technology is more likely to happen when someone shows them how to use it (Czaja, 2015). The availability of support lines and people trained to help older people when they encounter issues with the system also adds to a positive experience (Czaja, 2015; Marchibroda, 2015; Wagner et al., 2010).

5.1.4 Communicating the older user's experience: the use of personas

The whole context surrounding the older user needs to be taken into account when designing for this group. Older users' needs, preferences and capabilities have to be known and addressed in order for a system to be successful (Czaja, 2015). Research demonstrates the vital importance of the inclusion of a range of appropriate disciplines when designing for older people. As Wagner et al. (2010) stated, computer use by older adults is, by its very nature, a multidisciplinary topic. To capture and account for the differences in engagement with technology (compared to younger people), the unique impact of changes in physical and cognitive abilities etc., it might not be enough to solely have designers and engineers involved. Including, for example, psychologists and medical researchers

increases the chance that the team will explore any development from different angles (Khosravi and Ghapanchi, 2016; Wagner et al., 2010). Medical researchers can also help categorise the clinical benefits and cost-effectiveness of the ICT project (Khosravi and Ghapanchi, 2016). The former is fundamental for smooth adoption of ICT by older people, the latter will be important for funding agencies. In other words, a blend of disciplines is needed to make ICT successful

Having engineers, designers and e.g., psychologists in a multidisciplinary design team can cause challenges in communication. Professionals from different backgrounds and various fields differ in opinions, use of language (terminology) and knowledge about the end-user (Caddick and Cable, 2011; Nunes et al., 2010). Caddick and Cable (2011) suggested eight user experience documents (Table 14) that facilitate communication among the members of a multidisciplinary design team. These documents should be developed through solid research and intend to highlight important user requirements (ibid).

Personas (first on the list in Table 14) are not aligned with a specific part of a project. This means that they can be created early on in the project. As such, they can take shape during the research and development of the system, guide every part of it, and provide a quick reference when decisions need to be made about the design (Caddick and Cable, 2011). In addition, the concept of personas relates to 'case studies' in health and social care. **Case studies**

> *"explore and investigate contemporary real-life phenomenon through detailed contextual analysis of a limited number of events or conditions, and their relationships" (Zainal, 2007:1-2).*

Case studies have a long tradition in health and social care, with for example Yin (1989) and Stake (1995) as early influential drivers. Such linkages made them particularly suitable for this thesis, which stands at the intersection of disciplines. Personas allowed for a thorough integration and translation of the data. The term

translation was interpreted as, the process of identifying, clarifying and restating the requirements as deriving from the data (Young, 2004).

Table 14: User Experience Documents (based on Caddick and Cable, 2011)

DOCUMENT TYPE	DESCRIPTION
PERSONAS	Personas describe the ways in which your target group will use your service or system. The document shows the goals that these users will be trying to achieve with your service or system.
TASK MODELS	Task Models show what users do, their behaviour and specific requirements at each stage. It reflects what users need and the way in which or the exact time they need it.
USER JOURNEYS	User Journeys detail the specific steps users go through when completing a task or goal. As opposed to Task Models, User Journeys show the required interactions and the paths through a system or service rather than representing the desired user behaviour (Task Models).
CONTENT REQUIREMENTS	Content Requirement documents focus on user needs, in particular the text, images, sound and videos (content) that one must provide to enable users to fulfil their goal or task.
SITEMAPS	Sitemaps can tie all project documents together. They show the structure of the service/system and how it will be linked together.
WIREFRAMES	Wireframes hold all the individual teams (product, technical, management, design) together. They form a framework that shows how the service/system will be presented, how its content will be structured and where the data will come from etc.
USABILITY TEST REPORTS	Usability testing is a critical moment in a service/system lifecycle. These reports communicate uncovered elements, allowing the project team to discuss solutions that would improve the system/service for the users.

DOCUMENT TYPE	DESCRIPTION
FUNNEL DIAGRAMS	Funnel Diagrams are typically used in web design to visualise how users pass through certain routes on a website. They show the amount of users that go to a particular page, as well as how many complete the process, drop out, etc.

5.2 Creating usable personas

5.2.1 Personas in human-computer interaction

Two decades ago, Cooper (1999) introduced the concept of 'personas'. Prior to this, abstract representations of users were already known in marketing (Pruitt and Grudin, 2003). Even before Cooper's 'personas', similar methods such as user profiles and scenarios had been applied (Pruitt and Grudin, 2003). These persona-like efforts however were often unbelievable accounts of users providing only a limited understanding of how to use the characteristics. They were further poorly communicated among the disciplines involved in the design process and received little or no high-level support in organisations (Pruitt and Grudin, 2003). Another difference between personas and for instance scenarios is that the latter are not a generative method. Scenarios are used to capture key properties of specific situations, but they do not enable designers to think about new situations (Matthews et al., 2011).

For the HCI community, and UCD in particular, it was Alan Cooper who pioneered the idea of personas as part of his 'Goal Directed Design', which was a persona driven design process in 1999. Cooper (1999) defined personas as fictitious, specific and concrete representations of target users. In HCI, personas have proven to enable design improvement by ensuring the focus is on the user.

Personas are a way in which user profiles can be brought to life (Preece et al., 2015). Nunes et al. (2010) described personas as follows:

> *"Personas express the motivations, expectations and goals of a particular user group when using an artefact" (Nunes et al., 2010:4).*

Another description was given by Miller and Williams (2006):

> *"A persona is an archetype of a fictional user representing a specific group of typical users" (Miller and Williams, 2006:1).*

According to Caddick and Cable (2011), effective personas focus on the key goals that the user group has to achieve, the user's behaviours and their attitudes whilst completing their goal.

5.2.2 Personas are more than a tool for design

When Cooper introduced personas, he intended to limit assumptions made by design teams (Matthews et al., 2011). Without concrete material about a specific user, the word 'user' was found to be 'bent and stretched' by developers to justify almost any design decision (Atzeni et al., 2011; Matthews et al., 2011). Cooper referred to this as the 'elastic user'. As a design tool, personas were meant to help focus designs better (Matthews et al., 2011). By personifying important user characteristics for product design and marketing (Sinha, 2003), personas helped define the product by replacing the abstract 'elastic user', with the vibrant presence of a specific user who became a part of the design process (Sinha, 2003).

Over the years, personas became more than just a 'design aid' (Atzeni et al., 2011; Masiero et al., 2011). Putting personas at the centre of team discussions and thus placing the focus on the user, helped members to understand whether decisions were likely to help or hinder the targeted user group (Caddick and Cable, 2011). They also aided the allocation of development resources, contributed to product

positioning and sales (Matthews et al., 2011), supported decision-making (Chang et al., 2008; Masiero et al., 2011) and design evaluation (Chang et al., 2008).

Personas can convey information across a team involved in the development of a new service or system (Pruitt and Grudin, 2003). Typically, the design process of a system involves a multidisciplinary team. Personas can help assure the whole team is heading in the same direction (i.e. what the user wants from the system). They facilitate communication amongst the project team members, managers, customers and stakeholders (Adler, 2005; Atzeni et al., 2011; Chang et al., 2008; Pruitt and Grudin, 2003; Miaskiewicz et al., 2008), build a greater empathy for the target audience and develop a greater understanding of and identification with the user audience (Miaskiewicz et al., 2008). Personas have been used by designers in more creative or flexible ways and not (always) in line with Cooper's original intention (Chang et al., 2008). However, even when personas are not documented on paper, Chang et al.'s (2008) research showed that they could still exist in designers' minds and influence the design outcome. Not having personas explicitly articulated, does carry the risk that different people in the team are designing or working towards a slightly different type of end-user.

5.2.3 Critiques on the use personas

According to Caddick and Cable (2011), personas have two main goals: they help design decision making and they remind the team that real people will be using the system or service.

Personas can be useful for anyone who needs to make decisions about the design, especially when the team's knowledge about the end-user is limited. Although creating personas is an acknowledged method, downsides and/or risks have been reported. For example, personas can be thought of as being too 'artsy' and/or subjective (Miaskiewicz et al., 2008; Pruitt and Grudin, 2003). This is of particular

concern when personas are not based on research findings or, when the relationship between the personas and findings is vague (Miaskiewicz et al., 2008). When not based on data, personas might even look like they were designed by the design team based on their assumptions and/or what they personally like to develop (McGinn and Kotamraju, 2008). In science and engineering-based enterprises a lack of rigour can cause doubts (Miaskiewicz et al., 2008; Pruitt and Grudin, 2003). Another common problem in these spheres is that when personas are based on first-hand customer data, the sample size is seldom adequate (McGinn and Kotamraju, 2008). Others reject personas because they replace some of the actual user participation (Adler, 2005). Regardless of the reasons, when personas lose credibility among the project team members it is unlikely that they will be used appropriately in the design process (Miaskiewicz et al., 2008).

However, proponents argue that having personas replace some of the actual user participation is exactly the reason why, in certain cases, they are appropriate and useful (Adler, 2005; Matthews et al., 2011). They are seen as complementary to or a close alternative for participatory design as both serve the same goals (i.e. for example input from end-users) (Matthews et al., 2011). Participatory design can be accomplished for smaller groups, but can become a challenge when it involves e.g. special user groups such as older people (Moser et al., 2012). Access to participants can be restricted, whilst age-related changes can influence interaction and participation (see Chapter Two), et cetera (Moser et al., 2012). Furthermore, actual user involvement in the design work can also be seen as a hindrance rather than a facilitator (Adler, 2005; Matthews et al., 2011). This is particularly true when a very broad audience needs to be served. In such cases, personas are useful to ensure descriptions and inclusion of a range of different user groups (Adler, 2005).

5.2.4 Developing data-driven personas

5.2.4.1 General approach for the development of personas

As Chang et al. (2008) stated, there is no generally accepted or singular way of applying personas. Nevertheless, it is strongly recommended that personas are developed based on the findings of solid research and the experiences of real people (Caddick and Cable, 2011; Miaskiewicz et al., 2008).

The development of personas normally involves at least two main phases: identification and creation (Adlin and Pruitt, 2010; Caddick and Cable, 2011). Firstly, one has to **identify personas** based on the purpose for which they will be developed (Caddick and Cable, 2011; Miaskiewicz et al., 2008). This requires the developer to find distinct groups of users that constitute personas. Ideally, data are analysed so that patterns and segments can be identified. These patterns point out users' desired effect of using the system in terms of goals and motives (Blomkvist, 2002). Usually, the data will be of qualitative nature, but some studies have used this in combination with quantitative data (Miaskiewicz et al., 2008). Solely relying on quantitative data, however, presents a risk that personas become stereotypes that represent the designer's biases and assumptions (Adler, 2005).

Secondly, based on the gathered information, personas need to be **created** through writing a detailed narrative about a person (Chang et al., 2008; Faily and Flechais, 2011; Miaskiewicz et al., 2008). Once the personas have been formed, they are launched and communicated throughout the design process until the designed artefact is produced (Chang et al., 2008). Over the years, researchers have come up with different types of personas. For example, Chang et al. (2008) reported that a persona does not need to represent one user, but can be a conflation of users. This was also the case for the personas in this doctoral research. Bringing together a number of users in a single persona increases the

likelihood that a range of needs, perceptions, experiences and requirements are covered in the persona (Chang et al., 2008). However, no matter whether the data is from a person or a group of people, it is still based-on and emerged from the research and analysis (often user studies) (Ibid).

5.2.4.2 Specific framework: The Essential Persona Lifecycle

Regardless of their reason for development, personas generally require the collection of data to structure their overarching inclusions. Caddick and Cable (2011) suggested four critical building blocks in the process of persona development: key goals, behaviour, must do's and must never's. **Key goals** reflect what users want whilst the **behaviour** element should demonstrate that the team knows and understands what motivates the user to use the system or service. A simple and clear description of what the design team must do to support its users in their key goals and behaviour should be added to the persona; and finally any **'must never's'** that are to be avoided complete the persona (also see section 5.4).

Although these four building blocks gave guidance and direction to those constructing personas, they were not immediately supported by an explicit framework. Whilst personas gained popularity in the field of design and research expanded, solid frameworks for their development were unavailable for some time. This was the reason for Adlin and Pruitt's (2010) development of a practical guide to creation and use of personas in their book: *"The Essential Persona Lifecycle"*. Their lifecycle (or process) of developing a persona encompassed five phases as shown in the diagram in Figure 29. The lifecycle is a metaphoric framework that breaks the development of personas into different phases similar to those of human development.

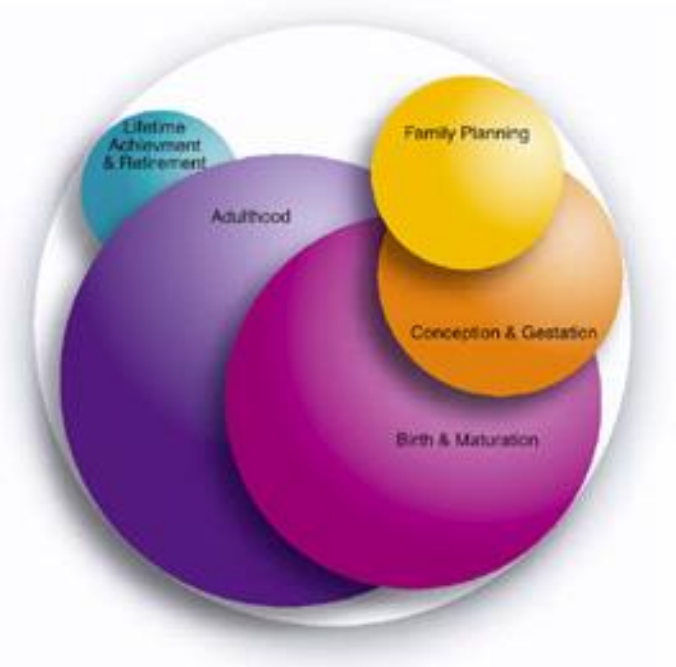


Figure 29: The five phases of the persona lifecycle (Adlin and Pruitt, 2010:3)

The persona lifecycle intends to support persona development by showing both the five phases and the magnitude of effort and importance of each phase (Adlin and Pruitt, 2010). However, as a cyclical process model with stages building on previous steps, it does not mean that each step needs to be followed with the same rigor. Adlin and Pruitt (2010) show developers of personas shortcuts throughout the process stating that *"the overall goal is to create helpful and well-used personas, not to follow the process to the letter"* (Adlin and Pruitt, 2010:3).

For this thesis, the focus was mostly on phase one (family planning) and two (conception and gestation) of the persona lifecycle (see below). The third, fourth and fifth phase involve the adoption of personas by the design team when developing a support system for care navigation. These three phases were beyond the scope of this research. Nevertheless, as they depend on the quality of the previous phases, they were born in mind whilst developing the personas of older people with multimorbidity.

5.2.4.3 Phase one of persona development

The first phase of persona development (family planning) focusses on problem identification (Adlin and Pruitt, 2010). In this phase, one is stimulated to think about e.g., what materials and/or data are available to use (Ibid). As such, before any actual creation of personas is done, problems and needs are evaluated and an exploration of available raw materials (e.g. user research data) takes place (Adlin and Pruitt, 2010). According to Adlin and Pruit (2010) this first phase encompasses making 'the decision' to use personas as a tool in the design process. However, sometimes it is not as much a conscious decision as it is a way to present findings (Vyas et al., 2006).

Mirroring Vyas et al., (2006), this study chose to use personas as a tangible and comprehensive method in presenting the research findings. This decision was made after the different options for communication of design requirements were reviewed (see section 5.1.4). Apart from their suitability in terms of their similarity to case studies and their process of development, they were also found to be the most comprehensive way to integrate qualitative and quantitative data (see section 5.1.4). Vyas et al. (2006) did not 'develop personas', but set them up as a retrievable, usable and communicable format for their data. This doctoral research went through the process of collecting, analysing and representing data, but the 'communicability' of personas was indeed an important factor in the decision of using them for a thesis at the intersection of disciplines.

Depending on the 'problem' that needs addressing, different data might be preferred to create the basis for the persona. Moser et al. (2012) designed a decision diagram for the creation of personas for special user groups (including older people). They aimed to identify the most appropriate approach, in terms of underlying data, to develop personas; that is, qualitative and/or quantitative data collection. It is important to tie personas to research results and careful analysis

(Moser et al., 2012). The decision about which type of data is needed, depends on pre-knowledge, skills, sample size and resources (Moser et al., 2012). Existing data on older people with multimorbidity and their way of navigating the care system was limited (see Chapter Three). Information on whether or not ICT could support these patients in their navigation task was not available. As such, this information needed to be collected. In this doctoral research new data were collected through a questionnaire and interviews. The questionnaire allowed for SNA of the PCNs of older people with multimorbidity (see Chapter Four).

Personas are goal-oriented tools by definition (Adler, 2005) and thus solely relying on questionnaire data would be somewhat reductive. In addition, the research focus of this study made the collection of qualitative data essential to gain deeper insights into the goals and needs of patients with multimorbidity in terms of navigating the care system. This allowed an understanding of the patients' experience and explored what these patients did, what frustrated them and what gave them satisfaction (Adler, 2005). The study findings in relation to these aspects can be found in the result section of this chapter (section 5.3).

Regardless of when, how or why the decision was made to use personas, a solid plan for the rest of the persona development needed to be created to ensure the second phase could begin (Adlin and Pruit, 2010). The second phase (conception and gestation) was fundamental to this doctoral research. Data needed to be turned into information and information, in its turn, into personas (Adlin and Pruitt, 2010).

5.2.4.4 Phase two of persona development

A persona represents a group of users, but is written in the form of a detailed narrative about a specific, fictitious individual (Miaskiewicz et al., 2008; Preece et al., 2015). It is almost a model of a user that focusses on the individual's goals. That means that personas are not descriptions of real, single nor average users,

neither are they just fantasies (Blomkvist, 2002). To help build strong and valid personas, six steps identified by Adlin and Pruitt (2010) were followed in this thesis (Figure 30).

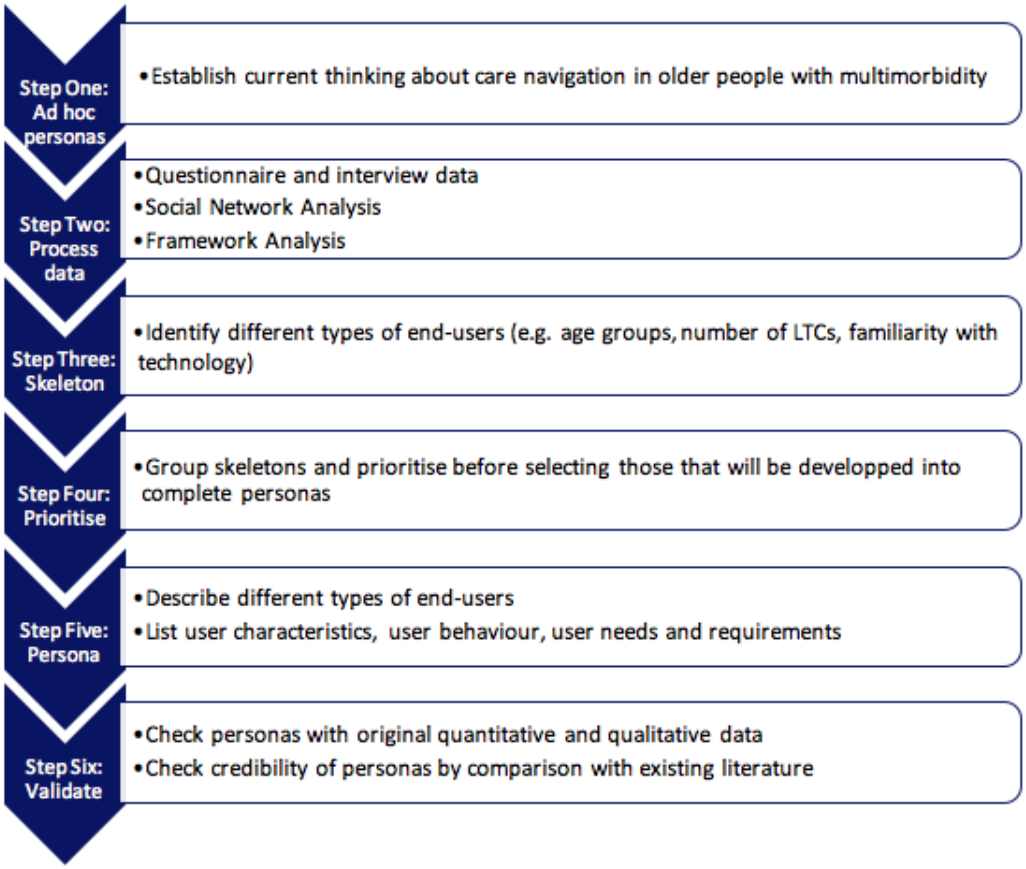


Figure 30: Six steps towards data-driven personas

Step 1: Identification of ad hoc personas

According to Adlin and Pruitt (2010), this step often results in personas that largely represent assumptions, but provide a first structure for data processing. Ad hoc personas were created quickly and captured the current thinking about older people with multimorbidity, their care navigation and their needs for support. However, unlike Adlin and Pruitt (2010), this step was not based on assumptions, but on the information that emerged from the scoping review (see Chapter Three).

Previous studies have used ad hoc personas as intended end-results of projects (Adlin and Pruitt, 2010; Atzeni et al., 2011), but in this thesis their purpose was to provide a first structure for data processing. Ad hoc personas would only be the initial stepping stone to robust development of data-driven personas. For the design of data-driven personas, Adlin and Pruitt (2010) advised that the entire six step process was applied.

Step 2: Processing the data

The personas created in this thesis, were grounded in empirical data collected from users who navigated their PCN on a day-to-day basis, i.e. within their 'normal' context (Atzeni et al., 2011). The data needed to be analysed, focussing on user needs, experiences, obstacles and facilitators in PCN navigation.

Depending on the purpose of qualitative research, the level of analysis has been shown to differ (Corbin and Strauss, 2014). For example, thematic analysis requires a different point of focus than, e.g., Grounded Theory. Where the former is looking for emerging themes, the latter seeks to build and test an emerging theory (Ibid). Grounded Theory requires a variety of data sources and many iterations in the analysis process (Corbin and Strauss, 2014). The focus of analysis in Grounded Theory is different than for instance in thematic analysis and tends to happen later in the research process (Ibid).

Using interviews to gather the material for personas, typically results in large amounts of data. Some of it is 'noise', other parts have some relevance and yet even further elements are highly important and relevant (Ritchie and Lewis, 2003). This can make data seem messy and voluminous (Ibid). Moving too quickly from these extensive raw data to more abstract accounts holds the risk of losing the overall view as a researcher. To prevent this from happening, Ritchie and Lewis (2003) described an analytical hierarchy; a process researchers 'move' through when analysing qualitative data. In short, one starts close to the data and moves

to a more abstract level of analysis as the research proceeds. During this process researchers increase their familiarity with the data. They start off with detailed readings, move towards systematically labelling the data whilst continually reflecting on what they have done and why they did it. The analytic process is completed by reviewing and refining the labels; focussing on key labels and relationships between them (Rapley, 2011; Ritchie and Lewis, 2003). This ensures researchers are not moving towards abstract levels too quickly, enabling a concentration on what emerges from the data.

Prior research has provided techniques to help process and analyse data, emerging the common characteristics or segments that make-up the core of the persona. For example, principal components analysis of data was suggested by Sinha (2003); Grounded Theory as a way to collect thematic concepts and their relationships was carried out by Faily and Flechais (2011), whilst Miaskiewicz et al. (2008) used latent semantic analysis as a way to create personas. Another approach to finding patterns in the data is through clustering the data (Maseiro et al., 2011). Many of these methods were introduced to ensure persona development was less subjective (Miaskiewicz et al., 2008). In this study it was chosen to adopt framework analysis (see sections 2.5.2.2 and 4.2.2) which enabled a systematic and transparent analysis of the data in relation to the research objectives and based on the Patient-Centred-Design conceptual framework.

As previously discussed, there is no universal method for persona identification and creation (Miaskiewicz et al., 2008). In this study, framework analysis (Ritchie and Lewis, 2003) was applied to the data on PCN navigation by older people with multimorbidity (also see section 4.2.2). This allowed a focus on common characteristic and experiences shared by multiple users (Miaskiewicz et al., 2008). These results are reported in sections 5.3.1 to 5.3.3.

Step 3: Creating skeletons

Following the themes and relations found in the data during the previous step, the processed data were evaluated. This meant that categories of users and/or subcategories were identified. The interviews were segmented focussing on people's needs and goals (Adler, 2005). Keywords were sought in the interview data to represent patterns that would help find important behavioural variables (behaviour mapping) (Adler, 2005).

With the use of framework analysis (see also Chapter Four), interviews were coded line-by-line through a continuous and iterative process (Ritchie and Lewis, 2003). Interview transcripts were read repeatedly, increasing the familiarity with the data. Gradually codes were created that first remained close to the actual words of the participants and moved to more and more abstract levels as analysis continued and developed. In this process, the focus was on exploring information in relation to tasks, behaviours and attitudes; rather than stories and demographics (Adler, 2005; Caddick and Cable, 2010). The results of this process are reported in section 5.3.

Step 4: Prioritising skeletons

Personas sought to incorporate the character of the persona and tried to convey objectives, characteristics and challenges (Nunes et al., 2010) in relation to care navigation. Not all cases or skeletons could be further developed into personas (Pruitt and Grudin, 2003).

Previous research has highlighted the need to keep the number of 'characters' manageable. Whilst Caddick and Cable (2011) suggest that usually one persona would be created for each type of user, (representing specific user behaviours and goals), the ideal number of personas was found to differ across sources and dependent upon projects. For example, Pruitt and Grudin (2003) suggested that

between three to six personas should be applied, depending on the breadth of the product use. Adlin and Pruitt (2010) recommend a similar number (three to five) although again, they did state that it depended on the focus of the project. The complexity (or otherwise) of the project was the core factor for Miaskiewicz et al. (2008), who suggested a broader range (from as few as three to twelve). Balancing this somewhat contradictory advice, this study has produced a total of four personas based on the data.

By creating a number of distinct personas, it was intended to cover the whole range of behaviour. Ideally the behaviour of the personas should not overlap in order to keep the number of personas to a minimum (Blomkvist, 2002). A set of skeletons was identified (see section 5.3.4) that would be developed into four full personas (see section 5.4).

Step 5: Developing selected skeletons into personas

The main requirements for personas, as originally defined by Cooper (1999), are that they are based on sound field research and presented in text and/or image (Chang et al., 2008). Adding detailed data and narratives to the skeletons was found to give them personality and context, which led to fully developed personas. For example, naming the personas increased their usefulness in terms of empathy for the user and humanisation and facilitated referencing when used in design meetings (Caddick and Cable, 2011). Another element that strengthened personas was the inclusion of user experiences in the form of verbatim quotes (Caddick and Cable, 2011).

Pruitt and Grudin (2003) used a foundation document for each persona including goals, fears and typical activities. Similar elements were used in this thesis (see section 5.4) using Xtensio (2016) as platform for the creation of personas. As a toolbox, Xtensio (2016) was designed by a team of user-experience and user-

interface designers. It was found to allow for the necessary detail whilst still revealing user information clearly (Ibid).

Step 6: Validating the personas

Once the set of personas was developed, they were verified against the initial data. To be valid, final personas needed to reflect the data (Adlin and Pruitt, 2010). No other well-established method was found for the validation of personas. However, this study allowed for personas to be compared with both the qualitative data (and themes) and the quantitative data (and social networks). As such, the content of the personas was generated from the data in this study and validation was possible by comparing the personas with data on several levels (qualitative data, quantitative data and PCN graphs). The process of comparing the personas with the initial data, led to the final development of the four personas as presented in section 5.4. These four personas reflect those data that most frequently emerged in this doctoral study.

5.3 Results on PCN navigation and experience

A diverse range of elements that would help older people with multimorbidity in their PCN navigation was drawn from the interviews. In the process of developing personas, these elements were identified and clustered. As this PhD study focussed on ways in which ICT could provide this support, what follows should be read within that context. Data are presented in relation to the steps as proposed by Adlin and Pruitt (2010) and connected to themes five and six from the framework for analysis (see section 4.2.2.2).

5.3.1 Data on Step One: Older people's experience of PCN navigation

An insight was gained into PCN navigation by older people (or indeed users) with multimorbidity. The task of building, and subsequently navigating, one's PCN rested mainly on patients' shoulders. Certain factors were found to aggravate and others to facilitate effective PCN navigation.

From the interviews, the **time since diagnosis** appeared to be an important factor influencing PCN navigation. It was suggested that (unless the person had a medical background), the first LTC could lead to more concerns and issues relating to navigating the system than additional LTCs. Throughout the years many had learned to find their way around in their PCN.

> *"[...] I've always had a lot of health problems […] so I have always, ever since I was small you know… but yes, yes, it helped loads because I've always had to do it you know." (pp2)*

> *"I always feel sorry for the people who don't know what to do, don't know where to go and are stuck. No, I, I'm lucky that I can cope with most things and know who to approach you know, I'll find a way of getting there, like the chiropodist you know, when I couldn't get there and I really needed one…" (pp3)*

As experiential learning facilitated effective PCN navigation, it did not necessarily aid navigation when **issues were faced for the first time**.

> *"[…] the GP would give you euhm euhm contact the let's say the crisis team but now all the GP does is give you a phone number or an email address and then you you email. It's all good when you're well, but when you're not well, you don't want to be emailing and then you've got to wait 18 weeks for someone from the mental health team to contact you. You know, you fill in a,*

they send you a form and they're based in Sleaford or Grantham or something like that, which is 20 odd miles away and when… when you're, when I had that meltdown euhm the GP came to me "Oh but you was all right yesterday", I know I was all right yesterday but it just happened. Euhm, but you was all right yesterday so you don't need any input, you get on with it […] all they do is give you a phone number and then and they send you an email with a questionnaire, which I, which I couldn't answer it […] I, I get, I got confused, I that I couldn't reply to the email, I didn't know how to do it. I know it sounds stupid, I can email and I'm not stupid, but at that time when I wasn't well effectively I couldn't do it, I couldn't do it so what was the point? You know, I couldn't even think of my own name at that particular time, I couldn't, I couldn't, I couldn't do it. Have to sit there and answer questions, like type in a box which wouldn't let me type in the box, in the end I just deleted it and I didn't bother." (pp4)

"So, this was the thing, I went to see my G.P. and […] I was hoping that the G.P. would send you to see some specialist physiotherapist or, or something but they didn't. All they sent me to see was the dietician. Yeah, a little bit of what she told me was...; but lots of it I already knew and lots of it unfortunately yeah just wouldn't work you know […] most of what she has said is not […] it just isn't relevant really, it just doesn't work really." (pp7)

Patience was often (n=7/7) mentioned to be an important asset for PCN navigation. For example, the time spent in the waiting room when attending an appointment was found to be unpredictable.

"I think, I have access to things… the only thing is like I said is sometimes it takes a while, that's really and that's probably because I'm impatient I don't know, but that's yeah… You know, the system is the system, there's nothing I can do about it so…" (pp2)

"But sort of thing somebody would make a big issue of and I would do at times and say it could be better organised to be done a bit more quickly. It might have been important for me because of the pain that I was in." (pp5)

5.3.2 Data on Step Two: Facilitators and barriers for PCN navigation

5.3.2.1 Proactive, experienced patient

The major factor leading to a satisfying navigation experience was found to be patients' **assertive, determined and proactive approach**.

"I think you have got to be proactive in your own case anyway, because it is the only way you are going to know anything. If you don't ask they presume you don't want to know." (pp1)

"INT: what made that (navigating) easier?
PP: Knowing the system and not being afraid to ask!" (pp2)

"Well I'm afraid I'm the one that sits and says "OK, I'm not moving from here" you know (laughs). I did this after I had the hysterectomy because nobody would tell me because I asked too many questions when the consultant came in. Cause I said "haven't seen him for days" and said "it's me I'm asking about" you know and I never found out why cause I had the hysterectomy and I had to go back there every every week at first for check-ups […] I was taking time off to go for the visits and I just sat and said "mind you I'm not going out of here until I know exactly why I'm having to have all these visits", and just looked at him, there was a staff nurse in the room and she just backed against the wall and said "nnnooo" (laughs) you know, I said "no I'm not moving anywhere", so he said euhm "nobody talked to you?" and I said "no they didn't they kept out of my way" so he just gave me my forms and things to have a look at and said "here, have a look" and I said "right, at least now I know", you

know I think communication is a good thing between people and I think quite a few lack the communication skills… (pp3)

This assertive and proactive approach was also needed for patients to find information. Patients felt that information was often spread out and they found it difficult to identify where to look for answers or solutions.

"PP: Ah, I think the resources of physiotherapists, should be more generally available. I think to help myself and other people's kit. I think the availability of information about alternative pieces of equipment that will also help you such as a wheelchair that I use for getting in and out of the shower and things like that […] would be better. The availability of information about equipment could be more freely and easily available." (pp6)

"PP: So you have lots of different points of call.
INT: So what, it would be ideal that they're all brought together?
PP: Yes that would be absolutely ideal.
INT: Uh-huh.
PP: In the perfect world...
INT: Yes.
PP: But yeah you would just go onto Facebook put yeah – "Ileostomy" or "Stoma" or whatever sort of thing and it would come up and it would say okay you can click on anyone of these four sorts of thing or whatever and we'll work with you." (pp7)

5.3.2.2 Design of the wider care system

The design of the wider care system formed the fifth theme for the framework for qualitative analysis (see section 4.2.2.2). A proactive approach was needed to effectively and efficiently navigate a PCN that was made more complex by the

design of the wider care system. The system did not, for example, always allow for patients to see the same provider.

"I: OK, so when you go for follow-up, is it always the same person or how does it work?
PP: No, it's the NHS my dear (laughs)." (pp2)

"You know… and then by that time the doctor has moved on or he lives somewhere else and they don't know anything about you, they don't know your history whereas many many years ago when I was a child you had a family GP…" (pp4)

"[…] I would sooner it be always the one person because my case has been fairly complicated sort of thing. Say for instance if it was the same person all of the time without a doubt they do get to know you a little bit sort of thing and they do get to know your problems a little bit. Because every time I get there one of the first thing that I have to explain is about the stoma and things, just in case you know it makes a difference with how I am feeling because they don't know and it's on your record somewhere, but yeah, they haven't seen that." (pp7)

The way the care system is set-up required participants to persevere in their navigation and deal with a number of complex barriers in accessing services, which could add frustration. The process involved in dealing with switchboards or finding the 'right' person to talk to was found challenging.

"But if I hadn't sort of kept phoning them I probably would have been just struggling on my own." (pp7)

"PP: It's like a minefield.
I: Mhm, how do you do that (navigation)?

PP: With difficulty, with difficulty… you know, you spend hours on the phone, press button A, press button B, number one for this, number nine for that, five for this… and all the while everything is a recorded, recorded answer, it's a program, everything is robotic, you don't speak to a person. It's a minefield, it's a battlefield trying to get through, you speak to one, "oh I can't deal with that I'll put you through to my colleague" and you explain everything over again and then "oh no you need to speak to such and such" […] and then I get frustrated because they've given me the wrong number. And so if they're doing their job properly, again like I say there's a right way and a wrong way." (pp4)

Sometimes patients were left at a 'loose end'; not having anything or anyone in place to follow-up on the situation. At other times patients felt they were sent 'backwards and forwards' across the system.

"Sit and wait I suppose, wait and see if they come back to me. I was thinking this week, actually if I got a contact number, but I haven't got a clue who to contact, don't know who it was euhm." (pp4)

"[…] the other thing I expected from hospital and I kept asking for it. Is you know, some sort of physiotherapy type of thing […] I was hoping that somebody somewhere would you know suggest physiotherapy or something. But there was absolutely nothing, you feel and this is why I had the mental health problem to start off with […] And nobody was giving you any advice." (pp7)

"[…] You then get a phone call from somebody on the switchboard, who then passes it on to somebody else, euhm, to a manager, to see you then, to see that you… you speak to the telephone person who then puts you on to somebody for, I I thought they were from the team, the safeguarding team but no they were only a receptionist that takes the minor details, who then passes

you on to somebody else who you speak to then for an hour on the phone, who then says I will pass your details on to a line manager to see if you were a, a visit from a social worker so you tell the story to five people… and then you might have forgotten something which happened in the first place or… you could have added a bit on, do you know what I mean?" (pp4)

5.3.2.3 Communication and interaction within the PCN

The communication and interaction within the PCN formed the sixth theme for the framework for qualitative analysis (see section 4.2.2.2). According to patients, the different parts of the care system formed separate entities.

"Mmh, we (physician and patient) talk a lot and euhm, he's just a separate service." (pp3)

"Erm, I think that I get the impression that they are pretty much in sort of silos really the outpatients." (pp5)

"[…] but they don't they are all separate entities that sort of thing." (pp7)

Smooth communication and interaction among the different parts of the care system was found to lead to more satisfying navigation experiences. However, for many interviewees (n=6/7) it remained unclear whether this actually took place. Participants relied on their assumptions as well as their experience to judge this.

"They should have one whole data, I know it would be a huge database, but they would be able to…" (pp4)

"Euhm, I don't… I assume that the GP sees things in the computer and reviews patients in their (nurses) care from time to time […]." (pp6)

"INT: What about communication between those two (GP and nurses)?
PP: I doubt it." (pp7)

In terms of the experience patients were able to identify interaction among providers, two main situations were sketched. Firstly, users identified situations that were perceived as 'positive' because a collaboration between professionals in their care system led to identifying and diagnosing the problem.

"Because it was the physiotherapist that first thought about the arthritis in my knee, cause I was kept having this pain and I went and said I think I want to go to the GP and say and that's how I, how they actually discovered I had it in lots of joints (laughs), so." (pp2)

"Euhm, communication between… mh, I would say that communication between GP and the consultant at the hospital or the radiographer are really good. When they picked up something and contacted my GP and then he arranged for me to have more tests done." (pp4)

In contrast, (and feeding into the second scenario), there were a number of situations where patients described that the lack of interaction had affected them negatively, leading them to feel 'lost' in the system.

"INT: So, can you tell me a bit about how communication works amongst those people in the hospital?
PP: How does it work between them? Good question, It doesn't […] no communication, one can't, one screen won't talk to the… I thought with all thing like computers and what have you and all the information they've got on you, because they know everything about you, like big brother, they know everything, even know what colour socks I'm wearing and things like that… euhm, but they can't communicate, no communication between one department and another…" (pp4)

"So the nurse next morning said 'Oh gosh they're going to hurt a bit when I pull those out,' […] and said 'I daren't take the other ten out because look at

them they are probably going to split open' she says. So I said 'Fair enough.' The doctor came the next day and said 'Why haven't you taken the other ten out?' But this was another nurse […]" (pp7)

With an apparent limited crossover of information between professionals, it was frequently the patients' task to bridge and connect the different parts of the system. The willingness and ability to do so were, again, found essential for successful navigation.

"INT: So in the end, do you feel you're the one providing the updates really? PP: I think, generally speaking yes […]" (pp2)

"I got no idea, because this this this woman from the [provider] team, she contacted them and said that they would contact you and yes they did, they phoned me up but euhm it's always a withheld number. So I don't have clue where, I don't where they even, I couldn't even tell you where they're based, I couldn't tell you, euhm… whether they're based at the… They're not base at the Lincoln city council are they? No, because that wouldn't… I don't know where they are, I haven't clue, I haven't got a clue. But it's been a long while… I know I did an assessment on the phone and they asked me loads of questions over the phone and then they said they would get back to me…" (pp4)

PCN navigation was reported to be facilitated by a good **patient-provider relationship**. Whilst seemingly primarily reliant on the patients' proactive effort, this also depended on the providers' people skills.

"PP: […] it would be nice if they could all speak the same language… I don't mean as in in English and French, but if they all speak the same, all the same words instead someone saying to me "oh we could signpost you this", "signpost you there", we could show you the way, which to me is the same thing, we can tell you how to do it and then you get someone who says "we

could signpost". Why don't you all speak the same… Speak the same, act the same,… yeah you got your different, your different words to…" (pp4)

Poor patient-provider communication sometimes undermined patients' trust in the provider and led to the decision of seeking care elsewhere.

"And so I had one referral and I really wasn't happy with that consultation so I asked for a re-referral to a different consultant in E.N.T. which then happened. And that was much better […] the consultant did not really erm, well give me sort of confidence in him. Something about him didn't you know… and also I really didn't like his manner with me. I didn't feel that, that he gave out a good recognition to the way that he you he didn't have to talk down to me […] And I didn't like that so no I felt there was insufficient respect and recognition in dealing with me […] And therefore I didn't, I wouldn't trust his judgement." (pp5)

Provider's people skills were also found to contribute to **provider-provider** communication.

"There again, it's the people working in it isn't it […] it's always been the same, you've get some who communicate and you've get some who don't." (pp3)

"And I don't have the impressions that there is certainly in terms of my care a lot of other communication between the G.P. and the hospital." (pp5)

Two levels of provider-provider communication were identified: interaction with colleagues within the same setting and communication between colleagues across settings. Again, mixed experiences were mentioned depending on patients' assertiveness and providers' communication skills.

"[…] after I had been in hospital for two weeks, that was the first time I actually sort of came in contact with the stoma nurses and what they did, although at

the time I didn't even know I was having an operation. They came with a black marker pen and say 'Where do you want your stoma?' I say 'I don't think I am having a stoma.' And they said 'I'm afraid you are', 'Oh no way, I don't think I am'. A little later on in the day I actually saw the surgical team and they say. 'Yeah you are going to have to have an operation' […]" (pp7)

As shown earlier, interviewees relied on their assumptions and experiences to judge whether communication and interactions among colleagues had taken place. On the level of provider-provider communication between colleagues, referral was mentioned as an indication that providers were interacting.

"INT: What about his (community chiropodist) contact with the GP?
PP: Yes, because you've to go through your GP to be referred." (PP2)

Only when patients received a copy of the letters sent between providers (e.g. hospital consultant to GP), did patients know with certainty that interaction had taken place. Many appreciated being kept in this 'loop'. Moreover, they valued receiving the copy and knowing what had been communicated.

"And I like now what they do do, which is sending me a copy of what; the report that they are sending to the doctor you. So you now get a copy of what they are saying to the doctor about you so that when you go to see the doctor; and on a couple of occasions I have taken the letters with me as well. This is when I have gone to see my G.P. for my check-up. I and then we talk about what the doctors say you know. About that the specialists are saying as well. So that's a good thing as well now. But the patient actually gets a copy of the specialist report so that you know what they are saying to your G.P." (pp1)

"I know the retinopathy when I have it, for the vision, this one comes, that they communicate with the GP and so does the optician, they send letters." (pp3)

A few participants (n=2/7) also pointed out that they perceived this communication back to the GP more difficult than from the GP. Whereas interviewees might be satisfied with the seamless process of referral from the GP, feedback from the consultant back to the GP seemed to take more time.

"Well I mean I think the communication, the formal request for an appointment made and then that seems to run very smoothly from my G.P. who sorts of books it on his desktop and […] And then the communication back then seems to be in electronic form that we get a report back and well I usually has a little gripe about something. It seems quite a long time between let's say an outpatient appointment and the report coming back to the G.P." (pp5)

As communication and interaction were found to affect PCN navigation, any absence was one of the major causes for frustration. For some interviewees (n=3/7) unmet needs and different expectations led to disappointment and distress.

"And then you've you have a problem and you you try and tell somebody over at the the home and they're not interested because this is semi-independent living so they're not responsible for you, then you think 'well who the hell is responsible for me?' I'm responsible for myself, I know, but you, it would be nice if there was just that little bit more input […]." (pp4)

"PP: Yeah which ridiculous! And that all they do is give you a phone number and then and they send you an email with a questionnaire, which I, which I couldn't answer it […] I know it sounds stupid, I can email and I'm not stupid, but at that time when I wasn't well effectively I couldn't do it, I couldn't do it so what was the point? […] in the end I just deleted it and I didn't bother.
INT: OK, so what would have been better for you at that point, could the GP do something?

PP: Yeah contact them or euhm, but because it's been taken out of their hands and all they have to do is give you the self self-referral which to me… I thought the GP was responsible for your wellbeing so therefore he has a duty of care, again, to contact if he felt you know that you, obviously he felt like I needed input, from the mental health team but didn't do anything about it, just left it, left it..." (pp4)

Finally, patients showed interest in having technology supporting communication with and between providers. They believed that modern technology should be able to bridge at least some of the gaps they currently experienced.

"INT: Okay. Is there anything you think technology could do in terms of getting these people to communicate?

PP: Yes, there is; there is because not one of those people; err not two of those people are actually on the same Facebook thing. So if, you know the ((Group Name)) the medical consultants and the stoma nurses and the G.P.'s and those; but they don't they are all separate entities that sort of thing." (pp7)

"PP: Yeah having it (the appointment and medication list she made on her computer) connected would be very helpful for people wouldn't it? And people who haven't necessarily got to time…" (pp2)

5.3.3 Data on Step Three: Summary of identified user support needs for PCN navigation

Based on the data from this study, user needs in terms of PCN navigation were identified. A specific look at patients' needs, pointed out that the provision and feedback of information could be improved. According to the participants, being kept in the loop (see section 5.3.2.3) of information exchange within the PCN would be a major advantage; especially since patients did not always see the same

provider. Uncertainty about communication among providers and information fed back from the specialist to the GP were two core domains for improvement. Similarly, frustration was expressed with gaps in follow-up (e.g. after discharge) and uncertainty, for example, about if and when home visits (see section 5.3.2.2) would take place (e.g. mental health team and waiting room). In direct communication with patients, clear and consistent wording of information (see section 5.3.2.3) was found to enhance PCN navigation. In the general provision of information, participants' needs that often remained unmet lay beyond direct medical issues. Patients reported that navigating information around equipment (e.g. stoma bags, wheelchairs), transportation options (e.g. disability transport), changes in lifestyle (e.g. what can and can they not do) and opportunities for social interaction (e.g. interest groups) was difficult (see sections 4.3.4 and 5.3.2.1)

Interviewees frequently pointed out the usefulness of technology in providing this information and closing gaps (see sections 5.3.2.1 and 5.3.2.3) that they currently needed to pro-actively undertake. Patients referred to the need of synergy between systems and the potential of sharing their own information (e.g. appointment logs and medication lists digitally kept by the patient) with physicians (see section 5.3.2.3). In addition, technology was mentioned to assist in social interactions and peer support (see section 5.3.2.1). Some suggested that connections between informal online support (e.g. Facebook groups and fora) and formal providers could be helpful. A frequent emphasis in the data was put on patients' wellbeing. The provision and access to information and services that could support patients in this dimension was found to be important.

With regard to technology supporting PCN navigation, patients mentioned the need of systems to be affordable, user friendly and usable even when feeling (physically and/or mentally) unwell (see sections 5.3.1. and 5.3.2.3). This also required bearing in mind the size of technological devices and the availability of

someone supporting them to use any system or teaching them how it could be used.

Alongside the information and communication elements, all interviewees emphasised the importance of having support 'on demand'. This could be professionals, informal carers or volunteers. Remaining independent whilst having people to draw upon when needed, was found the 'ideal' PCN scenario. As reported in Chapter Four, participants substituted formal care with volunteer-based and informal care to address their varying needs. Obstacles were mentioned in navigating formal care in the PCN, but it was especially this group of 'additional care services' that was identified when asking participants how they perceived the navigation of the PCN could be improved. Currently patients stated that they were required to be proactive in finding this information, but any actions were hugely limited owing to the lack of knowledge around what the care options might be or what services were available. In addition, finding the way through care services was found to be made more difficult with several switchboards and redirections involved.

5.3.4 Data on Step Four: Identified types of users

Based on the descriptive statistics as well as the interview data, participants differed in their ages, number and type of LTCs (see section 4.3.1). In addition, the size and structure of the PCN showed wide variation in the number of people involved and their roles (see sections 4.3.2 and 4.3.4).

Patients that would potentially use a PCN support system also differed in their experience with technology (theme seven of the framework for analysis, see section 4.2.2.2). Although none of the interviewees reported to actively resent technology, their familiarity with it varied. The majority (n=6/7) were frequent users of computers, laptops, tablets and smartphones. Only one interviewee was

found to have no access to a computer. She did use a handheld video game console, landline and answering machine. The reasons for technology use included looking up (health) information, supporting care (e.g. online prescriptions), social interaction, peer support and leisure (games).

Based on the data gathered for this study, four types of users were selected for the construction of personas (step 5: see next section).

5.4 Personas of older people with multimorbidity

Previous research has developed personas of older people in different contexts. Nunes et al. (2010) for example presented a persona of an older patient with diabetes to assist the creation a TV user interface, whilst Reeder et al. (2011) provided two personas of older users outlining their different technological abilities. Wöckl et al. (2012) developed personas of European older adults to aid designers, describing and highlighting the diversity and different capabilities among this population. These examples reflected the interest of using personas of older people in HCI. This study was the first to focus on data-driven personas of older people with multimorbidity in the light of fragmented care (see Chapter One) and the delivery of navigation support.

Data analysis and the identification of important observations in the data, led to segmentation. The data were clustered and labelled so that similar findings could be brought together (see results sections 4.3 and 5.3). The foundations for the personas in this study were based on patterns that were found across multiple individuals. The final four personas are compositions and represent multiple users as previously reported by Chang et al. (2008) (see section 5.2.4.1).

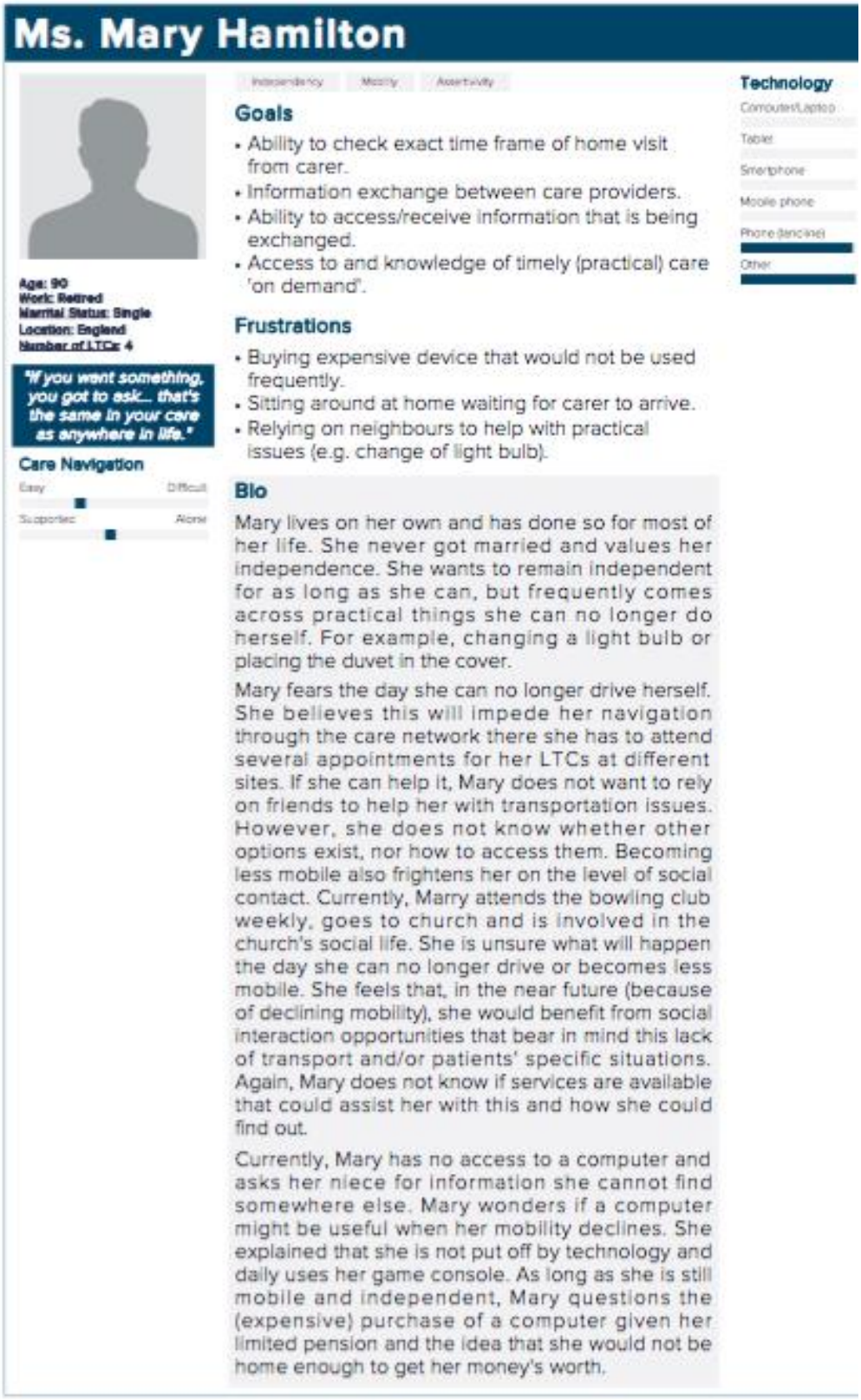
In line with Caddick and Cable (2011), the four personas state:

- The older person's key **goals** in terms of the specific tasks s/he wants to complete through the system and what s/he needs to know to reach their ultimate goal.
- The patient's behaviour in terms of a **narrative** communicating the context of this person's life to the design team. This ensures an understanding of what the patient is likely to feel and potential obstacles for using digital care navigation support.
- A selection of elements (frustrations) that designers **must avoid** in the system in order for the digital navigation support system to be feasible and acceptable to this persona.

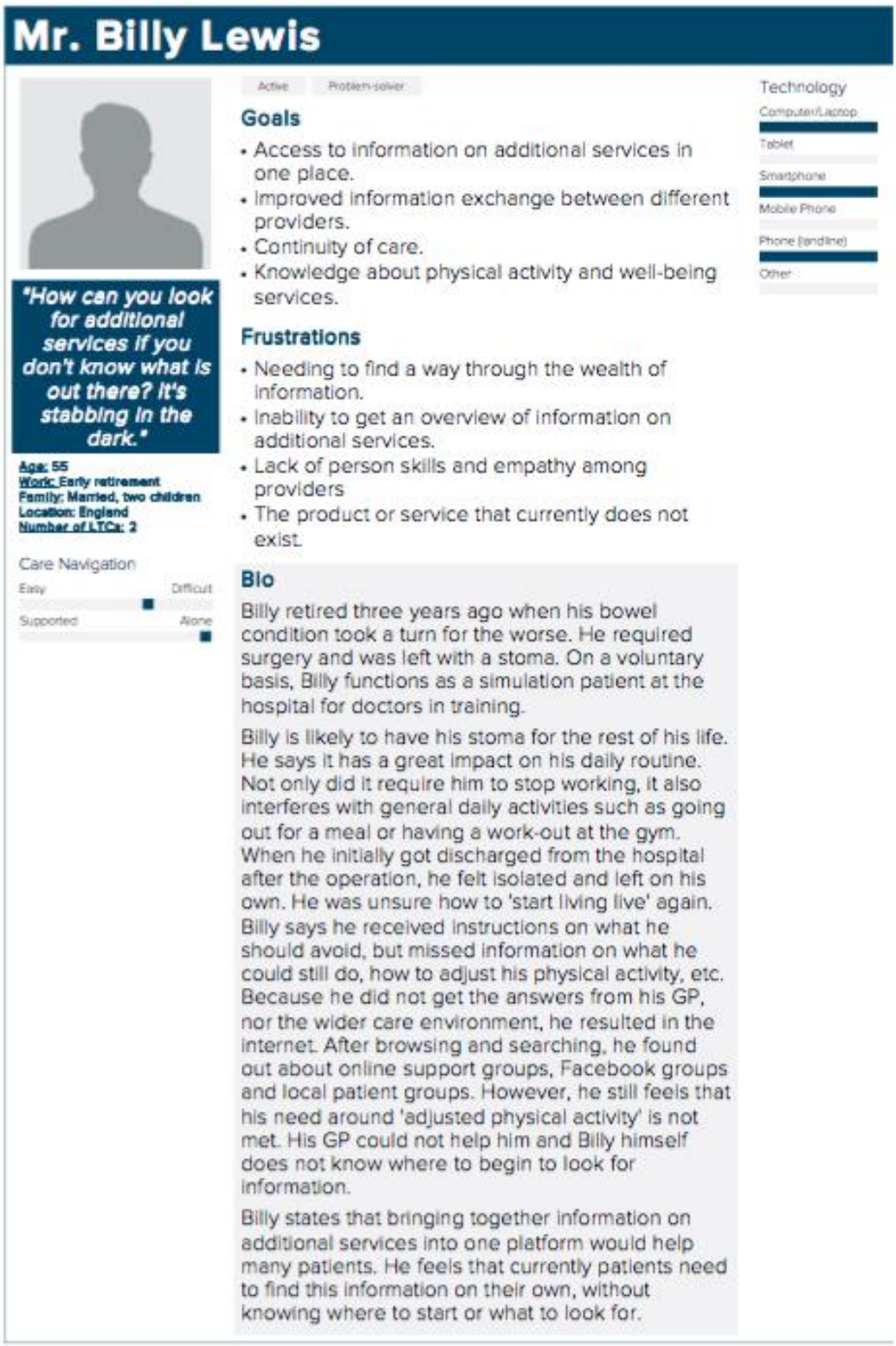
The personas in this study further included socio-demographic information (age, work, family status, location and number of LTCs) and the person's care navigation experience (easy versus difficult and feeling supported in their navigation or left on their own) to increase their reality (Caddick and Cable, 2011). As this study focused on older people, the technological devices they use on a daily basis are also represented in the persona overview. Overall, designers are advised to avoid confusing language (including inconsistent use of descriptions and terms) in the eventual end-product (as described in the results section 5.3).

The next pages show the personas that were identified from this research process. Using pseudonyms, the following four personas were created: Ms. Mary Hamilton (Persona One), Mr. Billy Lewis (Persona Two), Ms. Christine Stone (Persona Three) and Mr. Roger McQuire (Persona Four).

Persona One


Ms. Mary Hamilton
Age: 90
Work: Retired
Marital Status: Single
Location: England
Number of LTCs: 4
"If you want something, you got to ask... that's the same in your care as anywhere in life."
Care Navigation
Easy
Difficult
Supported
Alone
Goals
• Ability to check exact time frame of home visit from carer.
• Information exchange between care providers.
• Ability to access/receive information that is being exchanged.
• Access to and knowledge of timely (practical) care 'on demand'.
Frustrations
• Buying expensive device that would not be used frequently.
• Sitting around at home waiting for carer to arrive.
• Relying on neighbours to help with practical issues (e.g. change of light bulb).
Bio
Mary lives on her own and has done so for most of her life. She never got married and values her independence. She wants to remain independent for as long as she can, but frequently comes across practical things she can no longer do herself. For example, changing a light bulb or placing the duvet in the cover.
Mary fears the day she can no longer drive herself. She believes this will impede her navigation through the care network there she has to attend several appointments for her LTCs at different sites. If she can help it, Mary does not want to rely on friends to help her with transportation issues. However, she does not know whether other options exist, nor how to access them. Becoming less mobile also frightens her on the level of social contact. Currently, Marry attends the bowling club weekly, goes to church and is involved in the church's social life. She is unsure what will happen the day she can no longer drive or becomes less mobile. She feels that, in the near future (because of declining mobility), she would benefit from social interaction opportunities that bear in mind this lack of transport and/or patients' specific situations. Again, Mary does not know if services are available that could assist her with this and how she could find out.
Currently, Mary has no access to a computer and asks her niece for information she cannot find somewhere else. Mary wonders if a computer might be useful when her mobility declines. She explained that she is not put off by technology and daily uses her game console. As long as she is still mobile and independent, Mary questions the (expensive) purchase of a computer given her limited pension and the idea that she would not be home enough to get her money's worth.
Technology
Computer/Laptop
Tablet
Smartphone
Mobile phone
Phone (land line)
Other

Persona Two


Mr. Billy Lewis
Active
Problem-solver
Goals
• Access to information on additional services in one place.
• Improved information exchange between different providers.
• Continuity of care.
• Knowledge about physical activity and well-being services.
Frustrations
• Needing to find a way through the wealth of information.
• Inability to get an overview of information on additional services.
• Lack of person skills and empathy among providers
• The product or service that currently does not exist.
Technology
Computer/Laptop
Tablet
Smartphone
Mobile Phone
Phone (landline)
Other
"How can you look for additional services if you don't know what is out there? It's stabbing in the dark."
Age: 55
Work: Early retirement
Family: Married, two children
Location: England
Number of LTCs: 2
Care Navigation
Easy
Difficult
Supported
Alone
Bio
Billy retired three years ago when his bowel condition took a turn for the worse. He required surgery and was left with a stoma. On a voluntary basis, Billy functions as a simulation patient at the hospital for doctors in training.
Billy is likely to have his stoma for the rest of his life. He says it has a great impact on his daily routine. Not only did it require him to stop working, it also interferes with general daily activities such as going out for a meal or having a work-out at the gym. When he initially got discharged from the hospital after the operation, he felt isolated and left on his own. He was unsure how to 'start living live' again. Billy says he received instructions on what he should avoid, but missed information on what he could still do, how to adjust his physical activity, etc. Because he did not get the answers from his GP, nor the wider care environment, he resulted in the internet. After browsing and searching, he found out about online support groups, Facebook groups and local patient groups. However, he still feels that his need around 'adjusted physical activity' is not met. His GP could not help him and Billy himself does not know where to begin to look for information.
Billy states that bringing together information on additional services into one platform would help many patients. He feels that currently patients need to find this information on their own, without knowing where to start or what to look for.

Persona Three

Ms Christine Stone

Age: 60
Work: Early ill health retirement
Family: Divorced, one son.
Location: England
Number of LTCs: 6

"The care system is a minefield, a battlefield for patients."

Care Navigation

Easy	Difficult
Supported	Alone

Critical · Vulnerable · Tech-savvy

Goals

- More efficient and effective access to services.
- Access to the correct contact details of the right providers.
- Feel supported, heard and understood.
- Access to the full medical health record.

Frustrations

- Having to repeat personal history.
- Dealing with several intermediaries before accessing the 'right' person.
- Being assumed to bridge between providers and fill the gaps in the system.
- Receiving 'wrong' or confusing information.

Technology

- Computer/laptop
- Tablet
- Smartphone
- Mobile phone
- Phone (landline)
- Other

Bio

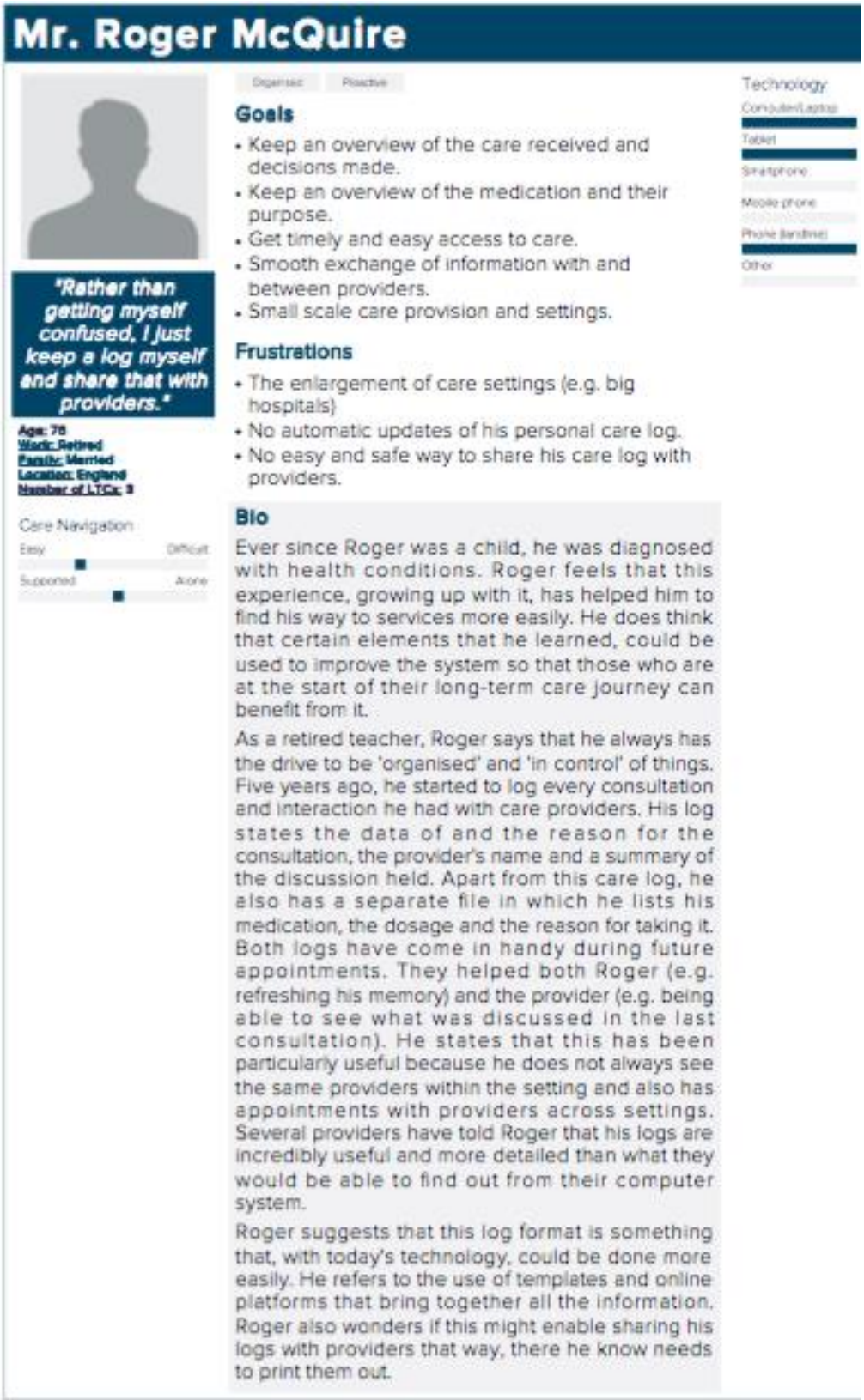
Christine lives on her own ever since she got divorced. She retired early due to her multiple long-term conditions. Two years ago, Christine moved to semi-independent living. She explains that she lives on her own, but every morning and evening wardens will come and check on her. At lunch time, she goes to a central lunch hall where the food is provided to her.

Christine currently finds navigating the health and social care systems a struggle. She feels that nothing is straightforward and that she has to go through several people and steps in order to get the care she needs. She gets frustrated every time she is given the 'wrong' contact details or confusing information. When she eventually reaches the person that can provide her the care she needs, she feels that they do not understand her situation (i.e. the fact that it is not just one problem, but a whole complex of health issues). Apart from the practical implications (e.g. getting the wrong contact details) this struggle is affecting her mental health. Christine is desperately seeking ways in which she can contact and access the right providers, but feels as if she is just a 'number' and is send from pillar to post.

Christine feels she is left on her own to figure out how to navigate the care system. Frequent disappointing encounters with formal services have left her reluctant to ask for help. On the odd occasion that she does seek help or support, she feels that it does not meet her needs. Particularly the bureaucratic structure of the health and social care system form barriers to her. She explains, for example, that the need to contact different services herself is often an impossible task when feeling distressed.

Christine is looking for support in this task of navigation. She says she finds it hard to believe that with computers and technology there is no better way of connecting information.

Persona Four



5.5 Conclusion

Regardless of an increased uptake of technology among older people, and the benefits and positive results, there still is an age-related divide (Czaja, 2015). Arguably there are several ways in which adoption and usability of systems by older people can be improved. However, the prerequisite is first of all to study HCI in the specific context of older people. Secondly, new technologies are more likely to be adopted and used among the older cohort if the team involved in the design interacts has an understanding of the end-users. As such research in HCI and older people is not only important, but also necessary if the generation gap (i.e. digital divide owing to age) is to be closed (Czaja, 2015). It is exactly this, studying the specific context of older people with multimorbidity and gaining an understanding of end-users for a digital tool for care navigation, that was established in this chapter.

This chapter contributed towards the third objective of this thesis. Theme five, six and seven of the framework for qualitative analysis were discussed in this chapter. Firstly, patients' care navigation experience was analysed, looking for elements for improvement of care navigation. Secondly, the interactions in the PCN were established and ways in which technology could facilitate these interactions were identified. Finally, this chapter provided concrete user-experience documents (personas) that can be used by the design team when developing digital care navigation support for older people with multimorbidity. The four personas are evidence-based documents for which information was gathered from a multidisciplinary perspective.

6

Discussion

This research focussed on the feasibility and acceptability of ICT to support older people with multimorbidity in their navigation through the care system. To explore this topic from a patients' perspective, three objectives were set at the start of the study: synthesise the current literature on the topic (1), identify and visualise the PCN of a range of participants (2), and deliver design requirements for the development of a digital care navigation support system (3).

At the start of this study, a new conceptual framework was developed combining the theories of patient-centred care, patient empowerment and user-centred design. This framework (Patient-Centred-Design) supported data collection and analysis throughout the three main parts of the study: the systematic scoping review (1), SNA of 62 self-administered questionnaires and seven semi-structured interviews among older people with multimorbidity (2), and the development of data-driven personas (3).

Stage one of the research connected to the first objective and brought together current evidence on care navigation in older people with multimorbidity. Out of twelve selected papers, only one focussed on multimorbidity in particular, suggesting a paucity of literature in this specific setting. The remaining 12 papers provided relevant information on in-person care navigation among people with single LTCs and the development of digital systems to assist patients' navigation. Findings of the scoping review identified patients' needs for navigation support (i.e. informational, practical and social support), but showed mixed results in terms of the way in which this support would be best provided. Terms such as 'obstacles' and 'frustration' were used in relation to patients' experience of

navigation, but little description was given as to what this entailed and whether patients with multimorbidity felt the same. These gaps in knowledge and practice of care navigation among older people with multimorbidity were addressed in the second stage of the research. This second stage related to the second study objective and delivered unique contributions to the field of HCI, SNA, and health and social care. To date, SNA had not been used in health and social care to visualise the PCNs of patients with multimorbidity nor to look at the process of navigation. Supplementing questionnaire data with rich interview data also allowed for contributions to the field of SNA itself.

Data on the use of technology, both for personal and health management purposes, expanded the body of knowledge in HCI and design for older people. The final stage of the study responded to the third objective. Whilst the hands-on prototyping and design of the digital care navigation support tool was beyond the scope of this PhD, data-driven personas of older people with multimorbidity were delivered as a tangible research outcome for developers.

This sixth chapter concludes the thesis and details key findings across the three stages of the research. Main findings are presented in relation to the study's objectives and the current literature, with highlights of the contributions (strengths) to knowledge, theory and methodology (section 6.1). Limitations of the study are provided in section 6.3 whilst section 6.2 reflects on the Patient-Centred-Design framework. Throughout this chapter and at the end (section 6.4), implications for further research and practice are considered.

6.1 Summary of objectives, key findings and contributions

6.1.1 Objective One: Synthesise the current literature on the topic

The systematic scoping review (Chapter Three) sought to gain a broad understanding of the experience of care navigation among patients with multimorbidity. This was the first review carried out on this topic and aimed to provide a wide overview of the literature. A scoping review was chosen over a systematic review (also see section 2.5.1) because of this necessarily broad focus.

Whilst the focus was on patients with multimorbidity rather than single LTCs, only one paper (Ravenscroft, 2010) was found to specifically look at this population. This suggested a limited availability of knowledge on care navigation in older people with multimorbidity. The remaining papers were selected owing to their relevance to (digital) care navigation in people with single LTCs (excluding cancer).

6.1.1.1 Navigation experience and barriers in older people with multimorbidity

Research findings in single LTCs on the navigation experience and barriers to any 'seamless' care' (Jackson et al., 2012) did demonstrate similarities with findings reported in patients with multimorbidity (Ravenscroft 2010). Patients with one LTC and those with multimorbidity, were both found to describe care navigation as a 'task' that could be 'challenging', sometimes 'frustrating' and not without 'obstacles' (Jackson et al., 2012; Ravenscroft, 2010). The challenging nature of care navigation was complicated by the lack of clear guidance on which service should be accessed (Bhandari and Snowdon, 2012; Ravenscroft, 2010). Those factors identified as causing or adding to patients' frustrations were: fragmented and disjointed health care delivery; difficulties in access and lack of access to adequate

information (Ravenscroft, 2010); and logistical issues (Ravenscroft, 2010) including the uneven scheduling of appointments (Jackson et al., 2012).

A further finding that was transferable between patients with single LTCs and those with multimorbidity, was the importance of experiential learning. Patients discovered and learned about the structures in the care system as they went along (Ravenscroft, 2010). Prior experiences helped patients to anticipate which services might be available and improved their understanding of organisation structures and processes (Jackson et al., 2012). Participants in the study of Ravenscroft (2010) revealed the existence of 'unspoken expectations' and preferences with regard to how they should interact with and access the care system (e.g. providers are reluctant to answer questions on the phone). Previous experiences were found to adjust patients' expectations; however, the study did not provide concrete examples of what patients thought to be those reasonable expectations that were later proven to be unrealistic (Ravenscroft 2010). Through trial and error, patients continued to discover the context of the care system, its loopholes and possible shortcuts (Jackson et al., 2012; Ravenscroft 2010). Ravenscroft (2010) summarised this as patients discovering the care system by *"analysing their observations and developing theories about how it worked"* (Ravenscroft, 2010:220).

The major difference found in the literature on care navigation among patients with single LTCs and those with multimorbidity, was the likelihood that any challenges and frustrations would be necessarily multiplied. Patients with multimorbidity were at risk of encountering care system challenges repeatedly as a result of their multiple interactions with the system. An exacerbation of patients' frustrations was found when challenges were faced for multiple conditions (Ravenscroft 2010). As such Ravenscroft (2010) suggested that multimorbidity could lead to a magnification of challenges and increased frustration as patients felt unable to rely on the health care system to be there for them (Ravenscroft 2010).

6.1.1.2 Navigation needs reported in the literature

To facilitate care navigation among patients, the need for three main types of support emerged from the literature: practical support, informational support and social support.

Firstly, practical support entailed assistance in obtaining access to appropriate services (Brossoie et al., 2010). As patients perceived the system to be fragmented, practical support ideally also covered logistical issues relating to appointment management, parking and transport (Ravenscroft 2010). Currently, help with the logistical side of care navigation often derived from patients' social networks, e.g. friends (Jackson et al., 2012). The latter was also found to be the case for older people with multimorbidity in this doctoral research.

Secondly, informational support was key for effective navigation of the disjointed systems. Brossoie et al. (2010) found that particularly information on home and community-based services would be sought. Since the discovery of available services was largely dependent on experiential learning, social support was mentioned as a way to bring more experience (albeit it second hand) to the picture (Jackson et al., 2012). Patients in the study of Jackson et al. (2012) also felt that the provision of information (and communication in general) by providers could be improved. The findings of this study confirmed this, identifying the need for information on additional 'low-level' services (e.g. gardening) and equipment (e.g. wheelchairs).

Thirdly, apart from its contribution to practical and informational support, social support also encompassed emotional and instrumental support such as help with finances (Jackson et al., 2012). For many patients, social support was provided by informal and unpaid carers, with similar structures found in the report for the National Audit Office by Morse (2014). This doctoral study showed that informal, unpaid carers were an important group of carers for older people with

multimorbidity. Not only did they provide support in terms of transportation, the data also seemed to suggest that they were often the group that provided social care to the participants. Overall, lower levels of (formal) SOCC involvement were noted across the participants compared to any other domain (HCH, HCC and IC). In line with prior findings (Humphries, 2015; Morse, 2014), many social care needs were addressed by the informal care network of older people with multimorbidity. This might be related to charges associated with using formal SOCC (Humphries, 2015; Morse, 2014; Thane, 2009).

6.1.1.3 Approaches used to address navigation needs

The papers reporting patients' experience and care navigation needs did not provide insights into how patients would want this support to be delivered. In other words, the way in which it was best to address the identified patients' needs was unknown. Two different approaches to deliver this support were explored in the literature. The majority of care navigation support programmes looked at in-person assistance, but recently an exploration of digital support delivery has begun. Again, literature on the available care navigation programmes specifically focussing on older people with multimorbidity (instead of single LTCs) was limited.

The scoping review revealed that **in-person care navigation** (e.g. care navigators or case managers) had been used in a variety of settings, but typically in relation to specific conditions (e.g. cancer) or particular points on the care continuum (e.g. transition from hospital to home) (e.g. Jackson et al., 2012). The innovative use of care navigators in the wider primary care setting was discussed by Ferrante et al. (2010). In-person navigators typically provided psychosocial support (e.g. making phone calls and updating physicians) to coordinate and access services (Ferrante et al., 2010; Manderson et al., 2012). With their roots in cancer care, in-person navigators generally held a nursing degree even though they rarely performed *"hands on clinical nursing duties"* (Manderson et al., 2012: 122). As their use

expanded and transferred to different care settings, the type of qualification needed by in-person navigators became subject to discussion (Ferrante et al., 2010; Manderson et al., 2012). Depending on the setting and qualification held, variations in focus of navigation support (e.g. social support or health care interventions) were found (Ferrante et al., 2010). However, the scoping review suggested that these differences might not have been as pronounced to patients as they were to physicians working alongside in-person navigators.

For patients, it was the positive impacts, such as improved quality of life, wellbeing and receipt of information, of in-person navigators that mattered the most (Albert, 2012; Ferrante et al., 2010; Manderson et al., 2012). For physicians, findings suggested that their opinion on the usefulness of in-person navigators might have depended on the qualification held by the navigator and thus the tasks s/he was allowed to carry out (Ferrante et al., 2010).

Integrating care navigators in group practices, such as the wider primary care setting, was perceived to be more challenging than in other (e.g. single disease) settings (Albert, 2012). Costs and a lack of onsite workspace were reported as main barriers (Ferrante et al., 2010). The lack of payment and reimbursement systems as well as providers found to be unable or unwilling to fund this role, challenged the implementation of in-person care navigators (Ferrante et al., 2010). This might particularly cause issues in the USA care systems where many patients are required to pay for their care packages.

Three studies provided insights into the possibility of **digital support** and to (help) address the current navigation barriers. Firstly, Yao et al. (2012) focused mainly on informed decision-making through the delivery of personalised information. This information was meant to aid patients in their efficient use of health care services. Secondly, a report *('The Role of Telecare in meeting the Care Needs of Older People: themes, debates and perspectives in the literature on ageing and*

technology') by the AKTIVE consortium (2013) discussed general ideas and evidence around technology in older people, including some of the considerations needed when designing for this group. Thirdly, Bhandari and Snowdon (2012) presented their process of developing a patient-centred, service-oriented navigation system. Although their on-going system design was situated on a local scale in Canada, their approach provided valuable lessons and insights (e.g. the role of service design elements in terms of the user's acceptance and usage of technology) for the study of digital care navigation support (Chapter Three).

Unique contribution of this study in relation to objective one

The complexity of the care system and finding the appropriate way through its separate parts (Ravenscroft, 2010) was found to be a problem for patients with multimorbidity. With previous research mainly focussing on single LTCs, it remained unclear what was to be understood by the 'problem' for those with multimorbidity. As shown in the results section of Chapter Five (5.3), findings from stage two of the study identified common problem areas that emerged from the semi-structured interviews. Among patients with multimorbidity who experienced difficulties in care navigation, challenges were usually situated on one or more of the following levels:

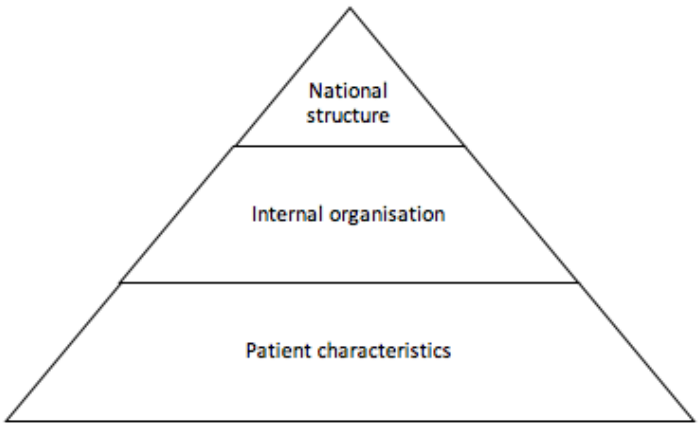


Figure 31: Three levels of navigation issues

As discussed in Chapter One, integration of care was found essential in order to meet patients' needs (Morse, 2014). Integration of care referred to the general concept of bringing services together (Shaw et al., 2011). Particularly in the current care climate that often displays fragmented care (see Chapter One), a lack of integration could add to challenges in care navigation. According to Freeman and Hughes (2010) integration was found to occur on five levels: the system, normative, service, functional and clinical level (Freeman and Hughes, 2010). Having established the three levels of navigation issues in Figure 31, the analyses in this study revealed that there are parallels between the levels of integration by Freeman and Hughes (2010) and the levels at which navigation issues occur.

Firstly, issues (and frustrations) for older people with multimorbidity could be related to the architecture of the national (English) care system which required patients to seek care in different settings (buildings and locations) and from different providers (depending on the types of LTCs). Similar to Ravenscroft (2010), this study found that patients struggled with knowing 'what' information was necessary and 'how' the information was shared across care settings. As a result, in line with Jackson et al.'s (2012) findings, participants in this doctoral research were occasionally responsible for updating the different actors (i.e. providers) in their PCN. Participants in this study often relied on their assumptions to judge if information and, what type of information, had been exchanged. The structure and processes of the care system were found to be a barrier in communication and interaction across settings, leaving patients with the perception that there were various silos of care. These finding aligned with the literature on care navigation (Albert, 2012; Bhandari and Snowdon, 2012) and confirmed the experience of fragmented care found in patients with single LTCs (Jackson et al., 2012) and multimorbidity (Ravenscroft, 2010).

Secondly, issues could occur on an organisational level (e.g. GP practice, specific ward at the hospital) which, for example, led to patients seeing different providers

within the same setting. Changes in providers were found to present a risk for lack of continuity of care, particularly as it was unclear to patients which information was shared among providers. This finding provided evidence for some of the concerns (e.g. fragmented care) raised in Chapter One. Whilst it is recognised that a large amount of literature explores the benefits of continuity of care, (e.g. Freeman and Hughes, 2010; Haggerty et al., 2003; Hill and Freeman, 2011), this thesis adds a new perspective (i.e. navigation of care) to those explorations.

A third set of issues related to patients' characteristics (e.g. attitude and resilience). This finding nuanced the magnifying effect (i.e. patients encountering the same obstacles multiple times and therefore an accumulation of frustrations) found by Ravenscroft (2010) in relation to multimorbidity. The results of this doctoral study confirmed that for some participants a magnifying effect might be true. However, the findings also highlighted that certain patient characteristics and experiential learning could mediate this effect. For example, for the two participants that disclosed a mental health issue, unmet expectations led to stronger feelings of frustration and disappointment when compared to the narrative from other interviewees. The sample size of this study does not allow for generalisation of this finding, but nevertheless the impact of patients' characteristics might need further consideration; particularly since limited literature was found on the topic of resilience in care navigation (among people with multimorbidity) (also see section 6.4.2).

Apart from the nature of challenges in navigating the PCN, this study contributed to and strengthened understanding of the PCN itself (see section 6.1.2). The literature suggested the involvement of multiple providers in the care for patients with (multiple) LTCs, all of whom seemed to be poorly connected with each other (Jackson et al, 2012; Ravenscroft, 2010). However, it was unclear what exactly the care network of this patient group looked like, who they received support from and thus what care navigation for these patients involved. This thesis provided a

unique contribution to the literature through the specific identification of those 'multiple' care providers (i.e. actors). The use of SNA allowed visualisation of formal and informal actors providing support to the older person with multimorbidity from a patient's perspective (i.e. PCN). Stage two of this study further added to the current body of knowledge by describing the roles and responsibilities patients allocated to these actors (also see section 6.1.2).

Although the scoping review revealed the types of support patients needed to facilitate care navigation, it remained unknown in which way this support should be delivered. Only Ferrante et al. (2010) discussed the implementation of in-person care navigators in the wider primary care setting and its challenges (Ferrante et al., 2010). These challenges (e.g. on-site work space) might be peculiar to the setting of primary care and fostered the exploration of other options, e.g. the use of digital support (Bhandari and Snowdon, 2012). This study investigated the requirements for such an alternative approach in order for it to be feasible and acceptable for use by older people with multimorbidity (also see section 6.1.3).

6.1.2 Objective Two: Identify and visualise the PCN

Previous research showed complex structures of patient care after discharge from the hospital, both in patients with COPD (Jackson et al., 2012) and among asthma patients (Cheong et al., 2013). Although prior studies indicated the involvement of 'multiple' providers (Parry and Coleman, 2010; Toscan et al., 2012) in delivering care, follow-up and monitoring of patients with multimorbidity, the extent of the (personal) care network involved, remained unknown. The second stage of this study (Chapter Four) identified and visualised the actors involved in the PCN of older people with multimorbidity and thus contributed to filling this gap. In the first instance, this stage of the study provided a description of what the term 'personal care network' meant to the interviewees. SNA was applied to data deriving from self-administered questionnaires and semi-structured interviews. A

detailed analysis of the latter was also conducted through the use of framework analysis.

Unique contribution of this study in relation to objective two

This was the first study using egocentric SNA to visualise the PCN of patients with multimorbidity. Cheong et al. (2013) used egocentric SNA in their exploration of patients' roles in multidisciplinary care (MDC), but relied solely on interview data. With a focus on interview data from patients with a single LTC (i.e. asthma) they visualised these patients' health care networks to explore the impact of patients' health connections on MDC processes and outcomes.

This study provided a description of the PCN by older people with multiple long-term conditions. Interviewees defined the (personal) care network as a hub or collection of people with whom they were connected and that provided support/care. This description of a care network comes close to how Fischer (1982) defined the **social network**: *"Sets of people with whom an individual is directly involved"* (Fischer, 1982:2). Fischer's definition emphasised the element of 'direct involvement', which was mirrored in this study (see discussion below). The novel use of egocentric SNA in this study, combining both questionnaire and interview data, resulted in contributions to knowledge on two levels (see 6.1.2.1 and 6.1.2.2 below).

6.1.2.1 Insights into the structure of the PCN

The use of egocentric SNA provided a comprehensive insight into the composition of the PCN both in terms of its structure and the division of roles (section 4.3). This was the first study to provide empirical evidence relating to the number of actors involved in the PCN of older people with multimorbidity through SNA. On average, patients were found to be surrounded by seven actors. However, this number should be interpreted with caution (as illustrated below), since this did not

necessarily mean an involvement of seven 'people' in the PCN but rather seven different 'sets' of people, some of whom could comprise more than one person. Moreover, the average of seven actors reflected the direct involvement in terms of actual care and support. It did not include administrative personnel (e.g. secretary), support staff (e.g. theatre nurses) or intermediaries (e.g. paramedics).

The use of framework analysis in combination with SNA allowed for an integration of the qualitative and quantitative data. The sociograms resulting from SNA were enriched with in-depth data on patients' experience of care navigation (section 5.3.1 and 5.3.2), communication and interaction in the PCN and patients' perceptions on roles and responsibilities within the PCN. From a patient perspective, the roles of primary, secondary, tertiary and informal care were outlined in addition to the responsibility patients perceived to hold themselves (section 4.3.4). With regard to their own responsibilities, besides self-care and disease management, the need to be assertive and proactive in accessing and receiving care repeatedly emerged. The findings further suggested that successful care navigation depended on patients' ability to communicate, and their perseverance. In terms of communication, 'asking' was found to be a major key to success and examples included asking to see the same provider, to be (re-)referred, to obtain information and enquire about additional support options (e.g. physical exercise). The importance of 'asking' and difficulties in obtaining appropriate and sufficient information from providers was also found by Jackson et al. (2012) and this study added concrete examples. Jackson et al. (2012) reported that patients were uncertain about which questions to ask and insecure about when to ask them. In this study, participants emphasised the usefulness of 'making lists' or keeping 'care logs' to help them communicate and remember the questions to ask different actors in the PCN. Aligned with Jackson et al. (2012) and Ravenscroft (2010), it was found that experiential learning played a major role in navigating the PCN. Patients with a medical background further benefitted from

knowing the routes, but even then their experience as a patient (rather than a provider) still added value.

6.1.2.2 Pre and post interview PCN maps

The application of two distinct methods for data collection (i.e. questionnaire and interview) frequently used in SNA allowed comparison of the data (section 4.3.3). Questionnaires and interviews were both found to be suitable methods for SNA (Scott and Carrington, 2011; Teddlie and Tashakorri, 2009), but previous studies did not combine the two within the same research. Drawing a subsample (n=7) from the questionnaire participants (n=62) for participation in semi-structured interviews, enabled the exploration of interviewees' data pre and post interview. Prior to each interview, a PCN graph was developed based on the questionnaire data of that participant. This graph was used during the interview and highly appreciated by patients. During the face-to-face interviews (n=6), participants held the map in their hands, using it to point out PCN actors whilst explaining their process of navigation. After free explorations of the more general questions (e.g. "What does the word 'care network' mean to you?"), using these graphs during the interview was found to refresh patients' memory by providing visual cues. This led to the addition of actors that they forgot to indicate in the questionnaire, but were involved in the interviewee's PCN. More depth (and additional actors) was created by participants explaining the existence of subcategories in the actors, for example 'family' was often divided into close family (children), brothers and sisters, cousins, etc. Moreover, participants who did not have their family nearby elaborated more in-depth on contacts in the community (i.e. neighbours, friends and wider community).

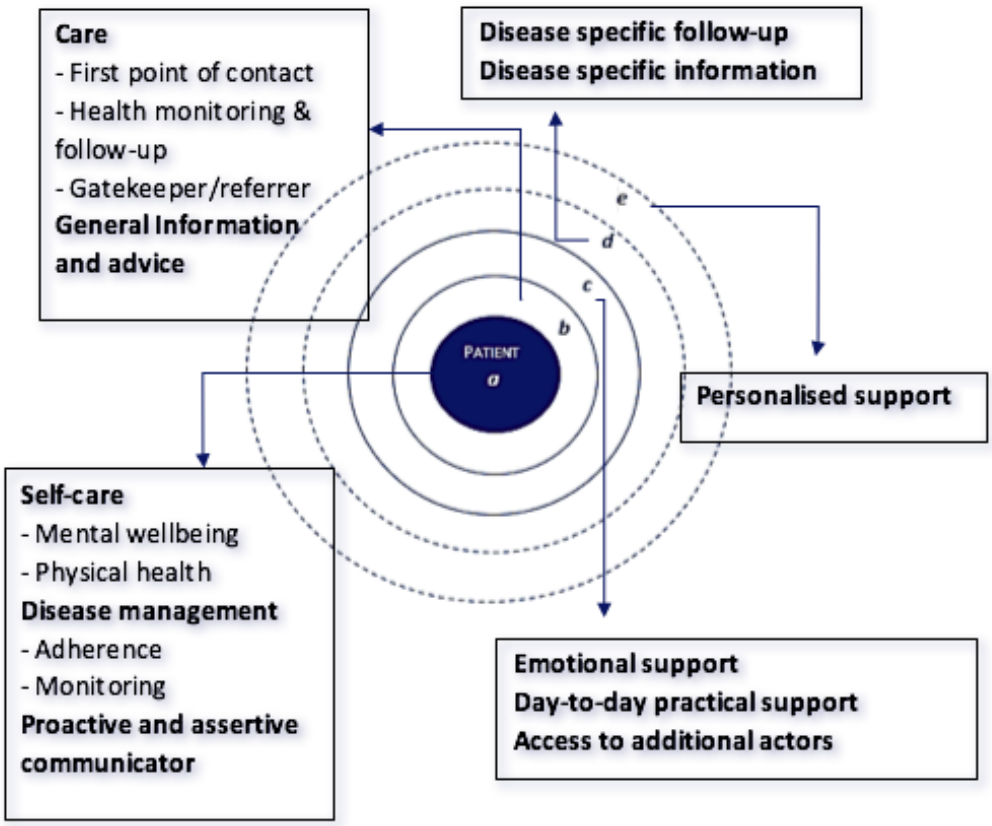
Seeing the graph also prompted patients to discuss the ties (i.e. lines) between actors, leading to the understanding that although the graph represented 'direct' contact with certain actors, patients had to go through different intermediaries

(e.g. administrative staff) before reaching that actor. Another asset to the use of the PCN graph during the interview was the establishment of 'assumed connections'. These were ties patients assumed, either resulting from experience or merely 'thoughts', to be present among the actors. Further research should be conducted to gain a deeper understanding of whether these assumptions were correct. All these additions led to notable differences in the details of interviewees' pre and post interview sociograms.

6.1.2.3 Details on PCN roles and responsibilities

Framework analysis of the interview data also enriched insights into how patients classify actors in their PCN. The lay-out of the questionnaire prompted patients to identify actors related to health care in the community (HCC) and the hospital (HCH), social care in the community (SOCC) and informal care (IC). The semi-structured interviews, however, did not strictly follow a classification and allowed patients to freely discuss their PCN navigation experience, barriers and facilitators through open-ended questions. This process revealed that, similarly to Cheong et al. (2013), patients' views on classes of actors in their PCN could be presented as shown in Figure 17 in section 4.3.2. Integrating the results from SNA into the themes deriving from framework analysis, led to a more comprehensive image shown in Figure 32. Figure 32 also shows the roles and responsibilities allocated to the five main categories of actors.

The, on average, seven actors that were involved in the PCN of older people with multimorbidity (questionnaire data) were classified in four categories: GP practice (b), informal network (c), experts depending on the types of LTCs patients were diagnosed with (d) and additional services (e) (interview data).



_____ = core group of actors in the PCN

---------- = actors subject to change in the PCN

a) patient; b) GP practice; c) informal network; d) experts; e) additional services

Figure 32: Five main categories of actors and their roles

This figure mirrored the central position and paramount role of the GP (practice) in patients' PCN. As detailed in section 4.3.2, the GP (practice) was the actor to go to when generally feeling unwell and for overall monitoring and follow-up of patients' health. However, both interview and questionnaire data revealed that 'care' was not the only, and particularly according to the interviewees often not the prime, responsibility of the GP (practice). The provision of information and advice together with functioning as a gatekeeper to secondary, sometimes tertiary

and even private care were two other tasks for which the patient mainly relied on this actor.

Whereas the involvement of the GP (practice) was found to be relatively stable over time, involvement of experts and additional services tended to change over time. Experts were added according to the patients' LTCs and sometimes became unnecessary when patients were stable, leaving the follow-up in the hands of the GP practice unless major health problems occurred. Data on additional services suggested that this was the 'level of care' where personalisation, at least in this study, mostly took place. A wide range of services was found, including gardening, transport, patient support groups, disease specific organisations and online fora. Patients relied on these to address needs (practical, informational and emotional) that were not met elsewhere in their PCN (e.g. information on equipment to aid mobility). Knowledge of different options, access to and navigation of these 'additional services' were found to be particularly suitable to be supported digitally (see section 6.1.3). Currently, patients often needed to find this information on their own, without knowing what to look for.

6.1.2.4 PCN characteristics according to age and number of LTCs

The use of statistical analysis enabled further exploration of the PCN data according to different groups (e.g. age and number of LTCs).

The **number of LTCs** was found to affect the overall size of the PCN for patients. Apart from relatively strong positive relations between these variables, analysis revealed that concretely for each additional LTC, another actor was added to the PCN. With regard to the different domains (HCH, HCC, SOCC and IC), the number of LTCs was found to mostly affect the structure of the PCN in terms of HCC and HCH actors, but less so for SOCC and IC. The number of LTCs could also affect the likelihood of receiving practical support from IC actors. Having four or more LTCs was found to significantly increase patients' chances to receive practical support;

i.e. they were four times more likely to receive practical support as the main type of support from IC actors compared to having two or three LTCs.

In this study, **age** was not found to affect the overall size of the PCN and only weakly correlated on a domain specific level. Additionally, the data did not show a significant relationship between age and the number of LTCs. This finding might have been the result of the inclusion criteria for the study, particularly the requirement to have at least two LTCs.

The type of support sought by participants did however vary according to their age, particularly in relation to HCH and HCC actors. Analysis revealed that older participants (>75 years old) were more likely to receive information and advice from HCC and HCH actors compared to younger participants (55-75 years old). This finding contrasts with Brossoie et al.'s (2010) results on the decreased likelihood among older patients to seek information. In their report Brossoie et al. (2010) pointed out that older people might have 'learned' about services throughout their lifespan by the simple necessity of having to access them to support their health and well-being. Bearing in mind the factor of experiential learning as found in other research (Jackson et al., 2012; Ravenscroft, 2010) and in this study, might indeed explain the finding. The increase in the number of middle-aged people diagnosed with LTCs (see Chapter One) and situating the lower age limit to be eligible for this study at 55 years, might have contributed to this contrasting result.

Further, it could be argued that the **time of diagnosis** (i.e. how long ago a LTCs was diagnosed), rather than participants' age, mediated the search for information, particularly since experiential learning was proven to be a prime factor in facilitating care navigation. No statistical proof was found for this hypothesis based on the (limited) sample in this study. All participants were diagnosed with their first LTC two or more years ago. Over half of the sample had the diagnosis ten or more years ago. This in itself might have affected the results compared to a

sample drawn from people who were recently (e.g. last six months) diagnosed with their first LTC. The latter, i.e., those people who have just started the navigation journey, emerged from the interviews as an important element to bear in mind when designing care navigation support.

6.1.3 Objective Three: deliver design requirements for a digital care navigation support system

In the third stage of this research, the study aimed to provide a clear understanding of how older people with multimorbidity currently navigate their PCN, what they want a (digital) care navigation support system to do for them and whether they will be able to understand and use such a (support) system. These three elements were in line with Wright and McCarthy's (2010) vision on user-centred design (UCD), i.e. developing an understanding of what the potential end-users want the system to do for them, how those end-users get this done at present and whether the they will be able to understand and apply the yet-to-be designed system (Wright and McCarthy, 2010).

6.1.3.1 User-centred design

The third objective involved the delivery of design requirements that would assist prototyping of a digital support tool for care navigation in this user-group. Researching design requirements for products and systems was reported to be one of the earliest stages in product development (Young, 2004). Moreover, when conducting UCD, it (often) comes before any actual designing takes place. As Wright and McCarthy (2010) pointed out: ensuring good design requires a dialogue with the end-user. Time and resources are required to build an understanding of the user, especially when it concerns a special users group with whom designers are not necessarily familiar (i.e. older people).

Traditionally the priority in technology-related fields (e.g. engineering, computing) did not immediately require that data be gathered from potential end-users (Wiegers, 2003), but rather allocated time and resources to actually design and develop the product (Gaver and Bowers, 2012; Young, 2004). The field of HCI has been changing this by focussing on the 'human' aspect in technology, computer interaction and the importance of the user experience (Wright and McCarthy, 2010; Preece et al., 2015).

As discussed in Chapter Five, older adults are a special user group with changes in physical and cognitive abilities and a different relationship with technology compared to younger populations. Some of the changes in ability result from the natural ageing process, others are caused by LTCs. Regardless of the 'reason', older people's use of a digital system as well as their needs with regard to that system are distinct from those of younger people.

6.1.3.2 Designing for older people

This study found that the number of guidelines for the design of systems for older people has increased (Luna-García, et al. 2015; Kurniawan and Zaphiris, 2005; Petrie, 2001), but the information available to design teams did not necessarily increase designers' understanding of the problems older users might encounter nor how to address these (Petrie, 2001). The findings of this doctoral research have filled in some of these current gaps. Whilst several ways have been documented to communicate the users' experience to the design team, this study decided to use data-driven personas. The reason for this decision was threefold.

Firstly, personas were found to be unrelated to specific stages of research. As such, they could be developed early on in a project and take shape as both the research and development of the system progresses.

Secondly, the concept of personas (i.e. providing a specific and concrete representation of a target user) showed similarities with the use of case-studies (but then with a focus on product development) in health and social care. Since this study stood at the intersection of care and technology, the use of personas was found to be especially suitable as it would add value and understanding to both fields. Research in health and social care has faced difficulties in disseminating and practically applying research findings (Glasgow et al., 2003; Kerner et al., 2005). Personas in this study were felt to increase the impact of the research.

Lastly, personas were found to allow a combined representation of the qualitative and quantitative study information. This integration of qualitative and quantitative data is specific to MMR, which made personas particularly suitable for this study.

Unique contribution of this study to objective three

As this was the first study to investigate the requirements for digital navigation support in care, the findings delivered several distinctive additions to research in HCI and health and social care. Three main contributions were selected for further discussion in this section.

Firstly, prior to the start of an HCI or computer science project, the proposal frequently requires specific statements about the expected outcomes of the study (e.g. characteristics of the product, the platform of the system to be developed) (Gaver and Bowers, 2012; Young, 2004). Throughout the duration of this research, the study was able to completely rely on participants and their needs. Therefore, it was possible to develop and shape the content of each of the stages in the study based on the findings from previous stages and thus adopt a thorough user-centred approach. This approach underpinned the credibility of the results and assured that the findings indeed derived from end-users rather than designers.

Secondly, the delivery of personas as a way to communicate as well as present the integrated data from this study provided a tangible outcome. Although the research behind the personas focussed on the navigation of the PCN by older people with multimobidity, the personas and data hold valuable elements in relation to older adults (with LTCs) in general. This means that the process of this study, its findings and the four personas could provide a basis for the wider field of HCI (that currently has limited or no access to this type of personas) and health and social care. That said, the study results and findings should not be generalised beyond their context without careful consideration (e.g. bearing in mind the context in which the data were gathered).

Thirdly, data-driven personas are the 'gold standard' in persona development. With limited time and resources, they are often based on data from user studies, rather than academic research set up specifically to provide them as an outcome. Since the latter is what this study involved, the outcome of this PhD provides a unique set of evidence based, data-driven personas.

6.2 Application of the Patient-Centred-Design framework

In the design of this doctoral study, the theories of patient-centred care, patient empowerment and user-centred design (UCD) were brought together into one innovative conceptual framework: Patient-Centred-Design (Chapter Two, sections 2.4.1 and 2.4.2).

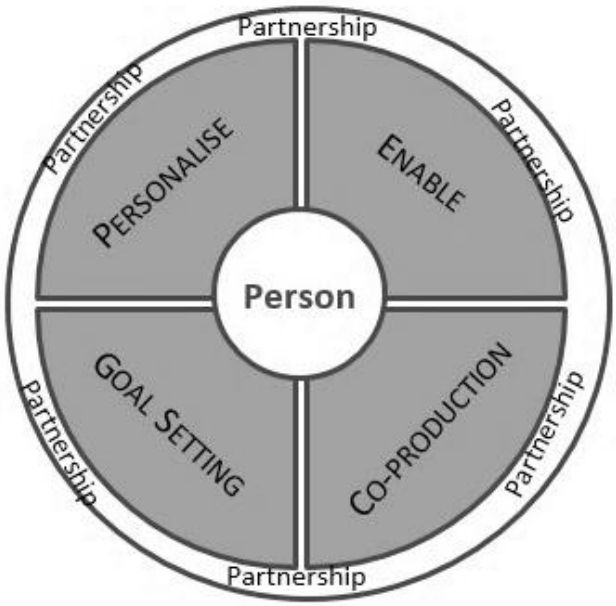


Figure 9: Framework of Patient-Centred-Design

Previous research in the design of technology within the care setting explored behavioural change frameworks for the development of interventions (Michie et al., 2011) and the use of experience based co-design to improve service development (Tsianakas et al., 2012). This was the first time the three theories were brought together into one comprehensive image that could represent both the care environment and the HCI field. With the number of studies conducted at the intersection of care and technology increasing, this juncture has become its own research field. The Patient-Centred-Design conceptual framework applied here is an important contribution to this nascent field. In particular, the design of technology for patients' use in care could benefit from this approach. Patient-Centred-Design included six different, but connected, elements: the person (at the centre), personalisation, enablement, goal setting, co-production and partnership.

6.2.1 Patient-Centred-Design in digital care navigation support

In this particular study, **older people with multimorbidity** were put at the centre of the research. From a patient perspective, their needs and experiences were explored in terms of PCN navigation and technology to support this. An understanding was gained of the **patients' goals**, how they currently conducted the task of PCN navigation (also see section 6.1.1 and 6.1.2 in this chapter) and how and with what, they wanted the system to support them. The study revealed that not all patients were satisfied with their PCN navigation, with issues mostly relating to the structure of the (English) national care system, the internal organisation of the separate parts of the system and patient characteristics (see section 6.1.1).

As summarised in the results section of Chapter Five (section 5.3), patients were looking for support in bridging current communication gaps between actors in their PCN. An extensive amount of literature has been published around communication in health care, both in terms of patient-provider and provider-provider communication (e.g. Baharav et al., 2003; Devoe et al., 2009). Moreover, Alpay et al. (2004) explored ways in which ICT could support health care communication. The use of ICT to support communication in the context of care navigation for older people with multimorbidity had however not been explored. The findings of this thesis suggested that patients could be supported by having a future system keeping them informed on which information was exchanged among the formal care actors. This would **enable** them to know exactly what had (and had not) been communicated and to formulate questions for their next appointment. In other words, it would give them the tools to be more certain and confident in playing the active role they are often asked to play in today's care environment (see Chapter One).

In addition, showing the process of communication and information exchange especially among formal care actors in the PCN, would allow patients to identify 'loose ends' (e.g. gaps in follow-up) early rather than having to 'sit and wait' without knowing who to contact. A future system could, for example, connect incomplete tasks (e.g. an appointment request that remains unanswered after a month) with providing options for inquiry (e.g. displaying the contact details of the actor that completed the step prior to the gap or enabling the patient to 'flag' the problem digitally).

The findings of this study suggested the usefulness of similar tracking options for home visits (e.g. community nurse) so that the patient would know an approximate time of arrival. For example, showing a progress bar based on the nurse's login or how many visits s/he had left before the patient. This could lead to the provision of an estimated time of arrival, for example based on average consultation times in the particular context.

A further issue reported by a few participants in this study related to the lack of clear wording of the information they currently received. As such, the future system should be consistent in the use of terms and/or descriptions.

Along with filling communication gaps, patients saw an essential system that brought together **personalised information** on, for example, assistive equipment, transportation options, lifestyle changes, social interactions and peer support. The data from this study strongly recommended the inclusion of services and personalised information focussing on patients' wellbeing. Currently, patients had to look for information and access it themselves, without knowing the different options that existed. Patients were found to substitute their formal care with additional services (see Chapter Four, section 4.3.4), including volunteer based care, informal care and third sector organisations. They used these additional services to address varying needs that were not met elsewhere in the PCN.

However, currently these services were found more challenging to navigate compared to some of the formal actors in the PCN. The reason for this finding would seem to be integrated with the patients prior or experiential knowledge. That is, whilst many had an understanding of the structures and processes of the different formal care options (experiential learning), the situation was different for additional services. Patients stated that they were unsupported in identifying and accessing such service provision and often had no guidance or tools to know 'where to start' to access such information.

Patients pointed out that technology would be a perfect way to bring the above and information on additional services together in **one platform**. The use of diaries, appointment logs and digital medication lists (see sections 5.3.3 and 4.3.4) currently kept by participants on their own initiative, could be further supported, assisted and integrated (e.g. with physicians' records) through technology. Some participants even suggested connections between informal support (e.g. Facebook groups) and formal providers. As the results of this study demonstrated that not all needs of the patient (e.g. wellbeing) are being met without the support of additional (non-statutory) services, assuring access to this information would aid an holistic approach in care.

Considering the challenge caused by switchboards and redirections, a future system, or indeed platform, should be **straightforward** in use. This means that ideally patients should be able to follow a minimum of steps to get to the right information or details on services. The need for an intuitive (or straightforward) design of the platform was strengthened by the finding that patients preferred to receive 'support on demand' (i.e. only when needed and otherwise be independent) whether it be through formal care, informal actors or volunteers. A further concern revealed by the analysis was the accessibility of and the navigation through the care system (and any tool to support this) by patients recently

diagnosed with LTCs. As such, the platform should be easy to navigate by regular and irregular, fit and distressed, tech-savvy and first-time users.

A future system should bear in mind its interoperability with existing systems and the potential to share parts with others (e.g. appointment log and medication list); including physicians. For the digital care navigation support system to be feasible and acceptable, the system should further be affordable, user friendly and usable even when feeling (physically and/or mentally) unwell. This required, for example, bearing in mind the dimensions and ergonomics of the devices (e.g. ease of readability of the screen and practicability of handling the device), the availability of someone supporting participants or demonstrating in a face-to-face encounter the different functions of any 'navigator' resource. Previous research mentioned the availability of help-line staff that are trained in supporting older users (Czaja, 2015, Marchibroda, 2015; Wagner et al., 2010).

6.2.2 Implications of Patient-Centred-Design for HCI

The development of the framework, its guidance in data collection and analysis and use during interpretation of the findings gave a real and concrete test of the components included in the framework. Based on the value of the theories encompassed in the conceptual framework and its overall use in this study, contributions can be made to the wider HCI field.

The Patient-Centred-Design framework was found to be useful and valuable in this patient-focused study. However, when using Patient-Centred-Design in the broader HCI setting (particularly when designing feasible and acceptable care technology), the 'person' at the centre of the design could well be any other care-related actor (e.g. formal or informal carer). Going forward, the term 'patient' in Patient-Centred-Design might not be the most accurate if used more widely in HCI for care. Having said that, this study did point out the complexity of the care

setting which suggested that the reasoning behind the framework would add value to care technology design (see section 6.4.3).

When using Patient-Centred-Design the patient (or indeed any person within the care setting that will be using the system) needs to be put at the centre of the design process. S/he is the expert in his/her life, experiences with care and technology, his/her care needs as well as needs in terms of technology. The care setting brings a very specific context to the design process. For example, when the system is intended to be used by patients, designers need to bear in mind that their health status might fluctuate throughout the use of the system and that their overall health might be different to that of younger and healthy users. Similarly, when the system is to be used by an (informal) carer, the system will be used for a particular (and potentially sensitive) goal, alongside other devices, tasks and occupations in a setting that is under pressure.

Designers should gain an understanding of this complexity surrounding the intended user of care technology in order to support the delivery of holistic care with technology. This means, understanding that the user might be an individual or require several people to have access to the same tool, the goals users aim to achieve might show more individual variation than for other technology and the support they want from the system might vary even within the individual.

In summary, throughout the design of technology for the care setting, one should focus on enabling the person for whom the technology is being designed. Ensuring that the system builds on the users' strengths and capabilities will be essential. In partnership with target users (i.e. both in terms of care services and technology) designers must not only co-design and co-produce a system that is tailored to the user's care and technology needs, but is also able to be complementary across the wider care context. Personalisation in this context, will naturally involve several dimensions (i.e. the user, the technology system and the care system) and yet

require the user interface to remain constant. The person for whom the care technology is designed will indeed be the expert, not only in his/her life, responsibilities and roles in care but also in the complexity of this setting and his/her technology use. Giving patients (or carers) a voice, will empower them and increase the likelihood of adoption and acceptance of the care technology. Empowerment in this setting should be twofold: empowering users by being part of the design process as well as delivering a product or system that supports patient empowerment as an outcome.

6.3 Limitations of the study

This section reflects on some of the key limitations of the study. At the start of the study and during its implementation, methodological and ethical options were considered before final decisions were made (section 2.5). Where possible, decisions were guided by evidence and/or available literature, but also encompassed the context of the study purpose. Three domains were selected for further reflection here: methodological considerations, the choice of literature synthesis and the development of the questionnaire.

6.3.1 Overall methodological reflections

6.3.1.1 Mixed method research

The use of a pragmatic philosophy and thus MMR allowed for a comprehensive exploration of the topic. It was acknowledged that the use of either qualitative or quantitative research could have provided information from a singular angle and potentially with a bigger sample. This might have increased the possibility to generalise the study findings. However, the complex nature of the phenomenon under study (i.e. care navigation in older people with multimorbidity) led to the

decision that a 'single' research approach would not be able to fully grasp the complexity of the topic (De Lisle, 2011).

Using MMR also carried the risk of delivering a study that used 'mixed methods' and thus 'mixed types of data' rather than an integration of the data (Giddings and Grant, 2007). Although two types of data were collected, the combined use of framework analysis and SNA was found to integrate the results and produce united outputs (i.e. sociograms and personas). However, this made a separate presentation of the data difficult. Where possible, data were separated to provide transparency and clarity for the reader, but it is acknowledged that in some instances this was not possible because of the MMR approach chosen in this study.

6.3.1.2 Study sample

All people aged 55 years old or over, who were diagnosed with at least two LTCs and lived in England (Lincolnshire for the interviews) were eligible to take part in the study. It was acknowledged that those with cognitive impairments (e.g. dementia) might not have been be able to recall services. This was a necessity to conduct egocentric SNA on the data. Similarly, older people with communication problems and/or limited English comprehension might have been unable to read and respond to the study. Although, for the purpose of this doctoral study, translation of the data collection materials to accommodate the specific needs of these groups was found infeasible, this needs to be born in mind when reflecting on the analyses or taking the results forward (i.e. beyond this study context).

Overall, the use of egocentric SNA was a feature of this study. SNA allowed visualisation and exploration of the PCN of older people with multimorbidity. The unique combination of questionnaire (n=62) and interview data (n=7) was an asset to SNA in this study and allowed the research question to be fully addressed. Although SNA was found the most suitable method for this research and its application led to advantages mentioned above, this method also brought along

some limitations that should be mentioning. For example, unlike more traditional methods for analysis, egocentric SNA does not allow sample size calculations. However, the robust theoretical development of the study supported the sampling process throughout the research. In addition, no information was available regarding the exact number of people living in the community with two or more LTCs (section 2.6.2), which would be needed for solid sample size calculations. The interview sample was based on saturation, which was reached after six interviews. One additional interview was carried out. However, it could be that further interviews, particularly with patients who disclosed a mental health problem, would have revealed new information. As no more patients in this category participated in the questionnaire, this remained unexplored in the scope of this study.

Although the final sample size in this study could be considered 'small' in comparison to samples in single quantitative or qualitative studies, in the light of (egocentric) SNA one could argue the opposite is true. In particular, for the visualisation of the PCNs and the establishments of design requirements. For example, the study of Cheong et al. (2013) involved data from 47 people. Nevertheless, those instances where the quantitative analysis went further than providing descriptive statistics (e.g. through carrying out sub-sample analyses) it has to be noted that sample sizes did become small and thus findings should be interpreted with caution.

As mentioned in section 4.3.1, the questionnaire sample did have an imbalance in terms of sex (male, female and unknown). Sex was not found to have an effect in the analysis, but it has to be born in mind that the majority of questionnaire participants were female. The interviews had a more equal ratio of male and female participants.

Although the size of the study sample might not be unusual, it was acknowledged that the sample technique could have affected the study results. For example, the strategies for dissemination of the questionnaire did not allow for an accurate calculation of response rates. Using the online questionnaire in the way this study did (i.e. disseminating the link to the online questionnaire), did not offer information on those who might have visited the online link, but decided not to complete the questionnaire. The design of the study, and the questionnaire in particular, made efforts to gain this information. For example, at the point of obtaining participants' consent, participants had four options as shown in Appendix 4. For those who indicated that they would rather not take part in the study, the software would register this. Only one respondent was found to have indicated this answer. However, others might have just closed the website without leaving any information.

Alongside from the online version, the questionnaire was also available in paper format. Again, participants who requested a paper version of the questionnaire through the online link were registered by the software. Three participants used this method to receive a paper version of the questionnaire. A total of 52 participants (three via the online link and 49 via other methods e.g. email) requested a paper questionnaire, 24 of which were sent back after completion. Although this represents a 46% response rate, a further 150 paper copies of the questionnaire were given to Age UK and none returned. The latter might have been due to the point at which these participants were approached by Primary Care Navigators from Age UK, i.e. at a time they were in crisis.

Without any information on non-responders and owing to the necessarily self-selected sample, the results cannot be assumed to be free of selection bias. This might be particularly the case in this study as interviewees frequently alluded to the need for patients to be 'assertive' and 'proactive' in order to have a satisfying PCN navigation experience. If assertive patients were more keen to communicate

their experience and thus more likely to participate, this will have impacted the results. A few suggestions to reach less assertive patients are given in section 6.4.2. Furthermore, since experience was reported as another important factor in PCN navigation, patients who were at the start of their multimorbidity journey (i.e. only recently diagnosed with multiple LTCs) might have given different answers to those who had their first LTCs years ago (i.e. this study sample).

In conclusion, those who participated in the study could have been different in terms of their characteristics and answers compared to those who did not participate. Therefore, results should not be generalised nor interpreted outside of their context without caution.

6.3.2 Reflections on the literature synthesis

Stage one of this study used a systematic scoping review to create an overview of the current literature on care navigation in older people with multimorbidity. The purpose of the literature review in this study was the provision of a broad synthesis rather than an in-depth exploration of a specific question (see Chapter Two, section 2.5.1). Another element that led to the decision of using a scoping review, was the limited availability of literature on care navigation among older people with multimorbidity. As such, this type of review was found to be the most suitable to fulfil the aim of synthesising the literature on the topic under study. However, scoping reviews generally do not intend to evaluate the quality nor the design of the studies included. This has been one of the main critiques on this type of literature review (Daudt et al., 2013; Levac et al., 2010). Arksey and O'Malley (2005) referred to scoping reviews as a way to 'rapidly' map the available literature on a topic. In line with Daudt et al.'s (2013) suggestions for enhancing the framework from Arksey and O'Mally (2005), this study's scoping review process was a systematic and thorough process rather than a 'rapid' synthesis. A systematic approach to the scoping review allowed for appraisal of the selected

papers according to the target population, type of intervention, comparison and outcomes (PICO).

Another observation in relation to the scoping review refers to the number of papers that focussed on health care. It was recognised that the use of different search terms might have yielded more social care specific papers. The reason to choose the term 'care navigation' was to acknowledge both health and social care. It was surprising that none of the studies included both. If the search terms were indeed more sensitive for health care related papers, one would have expected at least a few papers to cover both domains.

Finally, it was re-iterated in Chapter Two and Three that the scoping review focused on multimorbidity rather than single LTCs. Although the latter could have provided valuable insights, the main focus and interest of this study was on multiple LTCs as described in Chapter One. To acknowledge the unique challenges the combination of LTCs brings to patient's or user's, the focus remained on multimorbidity throughout the thesis.

6.3.3 Reflections on the questionnaire structure

Stage two of this study analysed and visualised the PCN of older people with multimorbidity. As no existing questionnaires would provide the data needed to answer the research question, this stage involved the development and pilot testing of a social network questionnaire. To gather the study data, participants had to be prompted about their contact with several actors. It was decided to enquire of the following care fields in the questionnaire: health care in the community and in the hospital, social care and informal care as these were the four domains frequently used in the literature.

Social network questionnaires carry the risk of being lengthy and repetitive as the same questions are asked to prompt further information about each actor (Scott

and Carrington, 2011). Even though efforts were made to keep the questionnaire as short as possible and the questionnaire was reviewed by carefully selected patients and members of the wider public, this study still echoed this finding. The online version of the questionnaire helped in this respect as it allowed for questions not to be shown depending on the answers to previous questions. The paper questionnaire on the other hand, directed patients to questions depending on the answers, but the first impression of the questionnaire would still be the length. It was stated in the paper questionnaire that several questions could probably be 'skipped', but the extent of the paper version might have been a barrier to some patients (see e.g. Cape and Phillips, 2015).

6.4 Key implications for practice and further research

This study provided an understanding of and insights into the complexity of care navigation in older people with multimorbidity. Whilst the study echoed previous findings around the challenges of care navigation, it also provided nuances and added new insights to the body of knowledge. Apart from the contributions and implications mentioned throughout this chapter a further three are discussed below.

6.4.1 Primary Care – General Practice

Chapter Four and Five detailed the structure and roles in the PCN of older people with multimorbidity from the patient's perspective. As discussed in those chapters, general practice was allocated a central position in patients' PCN. GP (practices) were found responsible for care (e.g. monitoring), coordination (e.g. secondary care) and navigation support (e.g. referral). However, the growing pressure faced by general practice (Clay and Stern, 2015), demands an exploration and assessment of its roles and responsibilities. For example, the increased

workload as well as complexity (Baird et al., 2016) might mean we need to consider which tasks could be carried out elsewhere or otherwise.

The results of this study showed patients' views on two out of five main burdens faced by general practice according to the Primary Care Foundation (2015); i.e. the processing of information from hospitals and other providers (1) and supporting patients to navigate (2). This doctoral study revealed that general practice's support in navigation might need to go beyond pointing patients to NHS care to additionally signpost and support routes to private health, social and third sector care.

The results of this study, particularly its implications for the development of digital navigation support, can help address some of the avoidable appointments in general practice. For example, the Primary Care Foundation (2015) concluded that 18% of GP appointments could have been avoided if: patients were directed to someone else in primary care; a clear care management plan or continuity of care had been established; or, patients were not to visit the GP when test results were normal. These elements could be (partially) addressed by a digital navigation system, empowering the patient and releasing some of the pressure in general practice.

In addition, GPs are required to keep up with changes in services and new options available to patients. This was another burden to general practice mentioned by the Primary Care Foundation (2015). Again, a digital platform could bring information on these changes together in a clear manner. Further research might benefit from, alongside patients' views, incorporating providers' needs for a digital care navigation system.

6.4.2 Further research in care navigation

Although this study provided unique contributions to the body of knowledge (e.g. understanding of the PCN of older people with multimorbidity), there is still a need for further research in this area. For example, the use of the NHS 111 service (non-emergency medical helpline in England and Scotland) might need investigation. Findings from this doctoral research implied limited to no use of this non-emergency number by participants. Information on the NHS 111 services however includes the statements of calling 111 *"if you need health information or reassurance about what to do next"*, *"if you don't know who to call"* and *"if you need medical advice"* (NHS 111, 2015). Further research could explore the NHS 111 data and identify how many encounters are related to navigation issues. For less urgent health needs, the NHS 111 still advises to contact the GP or local pharmacist in the usual way (NHS 111, 2015), but as pressure on GP practices increases, further investigation of the role of NHS 111 in care navigation would complete the care navigation picture. Similarly, the use of 'symptom checker' websites (e.g. NHS24 in Scotland or NHS Direct Symptom Checker in Wales) could add to the navigation picture or be developed and integrated into digital care navigators.

As the findings of this and prior research suggested differences in 'ease' of care navigation depending on experience, further studies might want to capture patients at the beginning of their navigation journey. This study tried to incorporate these patients by including an extra recruitment strategy through the Primary Care Navigators of Age UK Lincoln, but no questionnaires were sent back by patients. Active involvement, or indeed a sole focus, on patients that knowingly struggle with care navigation and/or were recently diagnosed with LTCs would be beneficial. This might also be a way to capture 'less assertive' patients.

Based on the results of this doctoral research, future work could also be conducted in the context of older people with multimorbidity whilst focussing on mental health. This area of work is suggested for two reasons. Firstly, the results from this study suggested that there may be real differences in patients' navigation experience when living with comorbidities and mental health challenges. Secondly, multimorbidity has repeatedly been found to affect patients' wellbeing and to increase their risk of depression. Previous research on mental health and resilience and care navigation has been conducted for example in children (Ungar, 2005) and HIV patients (Bradford et al., 2007). An initial exploration of the literature did however not yield any papers specifically investigating mental health, resilience and care navigation in (older people with) multimorbidity.

6.4.3 Future work in HCI and designing for older people

Section 6.2 described the implications of this study in relation to the wider HCI community and for those focussing on the design of tools for older people as well as for use in the care setting. This section stated that 'Patient'-centred Design might not be an accurate term going forward (i.e. when focussing on care in general rather than patient technology). As the field of care technology is still evolving and looking for new ways of care delivery and (digital) support in this matter, the findings of this study can form the basis for future initiatives.

For example, one of the next steps should be the actual prototyping (paper and or digital) and pilot testing of a digital navigation tool (e.g. a GPS for the care system) based on the personas delivered in this study. Paper prototyping can for instance be undertaken based on the personas and feedback from end-users could be gathered during workshops. The prototype might also benefit from input from Primary Care Navigators (such as those employed by Age UK Lincoln) or stakeholders. To increase the likelihood of acceptance and eventual adoption of technology (including the digital care support system), the usefulness of the

equipment will need to be emphasised (Eisma et al., 2004). To do this, stakeholders will serve an important function in communicating this; acting as 'champions' (Hartzler et al., 2013; Preuss, 2012). Older people often need a 'positive' experience with technology to stimulate the uptake of ICT (Wagner et al., 2010) and this is more likely to happen if someone shows them how to use it (Czaja, 2015). In-person care navigators can be key-players for the initial set-up of digital navigation support.

Another suggestion in the literature was to have support lines and people trained to help older people when encountering issues with the system (Czaja, 2015, Marchibroda, 2015; Wagner et al., 2010). Again, this might carry a particular role for in-person care navigators, for example 'training' support system personnel.

Conclusion

The study presented in this doctoral thesis aimed to explore care navigation in older people (aged 55 or over) with multimorbidity. Specifically, it focused on the investigation of design requirements for a feasible and acceptable ICT navigation support tool. This aim was achieved by the use of mixed-methods. Four sub-questions were addressed: 'What does the literature regarding care navigation in the setting of older people with multimorbidity tell us?'; 'What does the personal care network of older people with multimorbidity look like?'; 'How does this personal care network function according to patients?' and 'How can ICT support patients in their care navigation task and interaction in their personal care network?'

Chapter One of this thesis detailed the study context, outlining current ideas and changes in health care, social care and HCI. The first sub-question of this research was answered with the use of a scoping review. This was the first time the current literature on this topic was brought together. Results of the scoping review suggested a limited availability of research in the domain of care navigations in older people with multimorbidity. Based on previous research, it was possible to identify patients' navigation needs (i.e. informational, practical and social support), but not to clarify ways in which this support should be provided (i.e. by in-person care navigators or digital support). Information on the different ways to deliver this support revealed implementation issues for the use of in-person care navigators in the primary care setting (e.g. lack of on-site workspace). This strengthened the exploration of alternative methods for care navigation support, but no literature was found to specifically address digital care navigation support in older people with multimorbidity. It further remained unclear what patients' views were on the size of their (personal) care network and the roles they allocated to the people involved in their care.

These gaps were filled in the second stage of this study, answering the question of what the personal care network of older people with multimorbidity looks like. A study specific questionnaire and interview protocol were developed for data collection. Using an egocentric social network approach, data from 62 self-administered questionnaires and seven semi-structured interviews were analysed and visualised the personal care network. This provided an understanding of the structure of the care network surrounding older people with multimorbidity by producing graphs that showed the actors involved. On average, seven ('sets' of) 'actors' were found to be present in the personal care network of these patients. Additional framework analysis of the interview data allowed for the identification of the roles and responsibilities of these actors. Findings of this study revealed a central position of general practice with a strong gatekeeper and general monitoring role. Actors relating to the informal network were found to be important in the delivery of day-to-day support to patients and experts were consulted for condition specific needs. It was the level of third sector care, organisations and private care that showed personal differences according to the patient. These services were used to address patients' needs that were not met elsewhere in the personal care network. In addition, patients' roles and responsibilities were investigated. This was found to be particularly valuable in the light of the current ideas in health and social care; allocating an active role to the patient in his/her care plan. Data from this study showed patients' self-care and diseases management behaviours as well as their communication style. The latter was found to be an important element in relation to care navigation.

Findings demonstrated that patients' communication styles were linked to their opinion on how (well) their personal care network functioned. An assertive and proactive approach was found necessary for successful care navigation, suggesting that patients formed an important bridge between the different parts of the care system. A significant amount of interactions within and between parts of the care

system was invisible to patients, leaving them to 'assume' communication and/or information exchange had taken place. The occasions where patients were not able to persevere in their navigation, either because of their general health or because of the lack of information (e.g. no contact details), care navigation was found to be challenging and frustrating. Patients' characteristics were found to be one level that could lead to navigation challenges. Two other levels on which issues occurred were the national care system and the internal organisation.

Bringing together all the data and translating them into design requirements led to answers to the sub-question on how ICT could support patients in their navigation through the care network. Data suggested that the development of an ICT support tool, in the format of a platform, would allow for information to be brought together in one place. Currently, patients were left seeking for support either across different sources (with an increased responsibility of informal carers) or through their GP (practice). Although the latter was often not found to be a problem for patients, the imminent collapse of general practice as well as the increased pressure on health and social care, does question whether this is a sustainable option. In this final stage of the study, design requirements were reported in the format of data-driven personas; providing a tangible outcome, fit for use in practice.

Alongside the suggested areas for further research (e.g. on mental health, multimorbidity and care navigation) and future practice (e.g. the Patient-Centred-Design framework in HCI) throughout Chapter Six, a specific next step to take the results from this study forward could include the prototyping of a navigation support tool based on the personas delivered in Chapter Five. During this, paper and/or digital, prototyping process feedback should be sought form patients and potential stakeholders (e.g., care providers) who could be important for further development and later implementation (Wachter, 2016) of the digital navigation

tool. Feedback from these groups is expected to further shape the prototype before more large-scale pilot studies are conducted.

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List of Appendices

Appendix 1: Changes in LTCs included in the Quality and Outcomes Framework (QoF)

EVOLUTION OF LTCS IN THE QOF		
2004	**2010/2011**	**2015/2016**
Asthma	Asthma	Asthma
	Atrial Fibrillation	Atrial Fibrillation
Cancer	Cancer	Cancer
COPD	COPD	COPD
Coronary Heart Disease (CHD) including left ventricular dysfunction (LVD)	Cardiovascular Disease (CVD)	CVD
	CHD	CHD
	Chronic kidney disease	Chronic kidney disease
	Dementia	Dementia
	Depression	Depression
Diabetes	Diabetes	Diabetes
Epilepsy	Epilepsy	Epilepsy
	Heart Failure	Heart Failure
Hypertension	Hypertension	Hypertension
Hypothyroidism	Hypothyroidism	Hypothyroidism
	Learning disabilities	Learning disabilities
Mental health	Mental health	Mental health
	Obesity	Obesity
		Osteoporosis
		Peripheral arterial disease
		Rheumatoid arthritis
Stroke and Transient Ischaemic Attacks (TIA)	Stroke and TIA	Stroke and TIA

Appendix 2: Summary of Reported Benefits of ICT for Older People

EXAMPLE OF RESEARCH	POTENTIAL BENEFITS FOR OLDER PEOPLE
Wagner et al. (2010)	• Increased contact with family (especially grandchildren) and friends. • Bridged geographical boundaries and distance in general when limited mobility. • Beneficial in coping with grief.
Khosravi and Ghapanchi (2016)	• Supported people in their daily life, assistive technologies applied to help seniors with LTCs were found to be the most effective. • Positive effects of telemedicine on older adults' health conditions. • Effectiveness of telemedicine shown in patients with poor well-being. • Beneficial for social isolation, emotional well-being and social connectedness. • Reduced costs of health care by reducing hospital readmissions and fall injuries (positive results relating to fall prevention). • Improved quality of life, especially among older age groups.
Czaja (2015)	• ICT led to well-informed and empowered patients/caregivers. It helped them to make better decisions and enhanced the ability of patients to communicate with their providers. • Technology facilitated patients' ability to take an active role in the management of

EXAMPLE OF RESEARCH	POTENTIAL BENEFITS FOR OLDER PEOPLE
	their health (e.g. renewal of prescriptions and scheduling of appointments). • Technology allowed for greater access to personal health information. • The ability to track/monitor/manage health conditions (outside clinical settings) was mentioned as a positive effect. • Positive in preventing disabilities, enhancing mobility and quality of life as adults' age. This was found promising in terms of enhancing independence of older adults.
Huizilopoztli et al. (2015)	• Technology could support communication and support people in becoming active, independent participants in a digital-society. • ICT could improve the quality of life of older adults by offering better communication alternatives with their loved ones and thus reducing their loneliness and isolation.
Marchibroda (2015)	• Technology helped to address older people's needs, providing them with opportunities to receive the proper care and attention they need in an efficient, convenient and cost-effective way. • ICT was found promising for the promotion of exercise, support rehabilitation, improve medication adherence and provide care for those with severe dementia.

EXAMPLE OF RESEARCH	POTENTIAL BENEFITS FOR OLDER PEOPLE
	• Technology could bring health care and social connections to individuals in their own home, making it possible for older adults to live independently and age in place, in the comfort of their own homes. This would allow them to retain a high level of independence and control over their lives.

Appendix 3: Integrative Framework for Inference Quality

ASPECTS OF QUALITY	RESEARCH CRITERION	INDICATOR OR AUDIT
Design quality	1. Design suitability (appropriateness)	1a. Are the methods of study appropriate for answering the research questions? Does the design match the research question? 1b. Does the mixed methods design match the stated purpose for conducting an integrated study? 1c. Do the strands of the mixed methods study address the same research questions (or closely related aspects of questions)?
	2. Design fidelity (adequacy)	2. Are the QUAL, QUAN, and MM procedures or design components (e.g., sampling, data collection procedures, data analysis procedures) implemented with the quality and rigor necessary for (and capable of) capturing the meanings, effects, or relationships?
	3. Within-design consistency	3a. Do the components of the design fit together in a seamless manner? Is there within-design consistency across all aspects of the study? 3b. Do the strands of the MM study follow each other (or are they linked) in a logical and seamless manner?
	4. Analytic adequacy	4a. Are the data analysis procedures/strategies appropriate and adequate to provide possible answers to research questions?

ASPECTS OF QUALITY	RESEARCH CRITERION	INDICATOR OR AUDIT
		4b. Are the MM analytic strategies implemented effectively?
Interpretive rigor	5. Interpretive consistency	5a. Do the inferences closely follow the relevant findings in terms of type, scope, and intensity? 5b. Are multiple inferences made on the basis of the same findings consistent with each other?
	6. Theoretical consistency	6. Are the inferences consistent with theory and state of knowledge in the field?
	7. Interpretive agreement	7a. Are other scholars likely to reach the same conclusions on the basis of the same results? 7b. Do the inferences match participants' constructions?
	8. Interpretive distinctiveness	8. Is each inference distinctively more credible/plausible than other possible conclusions that might be made on the basis of the same results?
	9. Integrative efficacy (mixed ant multiple methods)	9a. Do the meta-inferences adequately incorporate the inferences that are made in each strand of the study? 9b. If there are credible inconsistencies between the inferences made within/across strands, are the theoretical explanations for these inconsistencies explored, and possible explanations offered?

ASPECTS OF QUALITY	RESEARCH CRITERION	INDICATOR OR AUDIT
	10. Interpretive correspondence	10a. Do the inferences correspond to the stated purposes/questions of the study? Do the inferences made in each strand address the purposes of the study in that strand? 10b. Do the meta-inferences meet the stated need for using an MM design? (i.e., is the stated purpose for using MM met?)

Source: Teddlie, C. and Tashakkori, A. (2009). Foundations of Mixed Methods Research. California: SAGE.

Appendix 4: Study Materials for Questionnaire

A) Study Flyer

B) Study Brochure

Get in touch

Jolien Vos

Graduate Research Assistant
and PhD student
Community and Health Research Unit
School of Health and Social Care
University of Lincoln
jvos@lincoln.ac.uk
01522 886934

UNIVERSITY OF LINCOLN

Version 2 – Dec. 2015

Study Information:

Feasibility and acceptability of using ICT to support older people with multimorbidity in navigating the care system

Get involved,
your opinion is important to us!

University of Lincoln

01522 886934

Hi there!

What is this study about?

The purpose of the study is to help us gain an understanding of the support you receive regarding your care and how you managed these different types of support. Based on this understanding we would like you to help us find ways in which we can improve care support for older adults with a number of health problems. The project has four main phases:

- Phase 1: Reviewing the literature
- Phase 2: Questionnaire
- Phase 3: In-depth Interviews
- Phase 4: Developing a tool to improve care navigation

Who can take part?

The questionnaire can be filled out by anyone who:

- Currently lives in England,
- is 55 years old or more and
- has at least two long-term health problems

For the interviews, we are particularly looking for people living in **Lincolnshire**.

Why take part in an interview after the questionnaire?

The questionnaire gave us an initial picture of those people that support you in receiving your care (care network). An interview allows you to give us more detail on your experience of 'what goes well' or 'what might be improved'. This gives us a better understanding and helps us in the process of developing a 'tool' that supports older people to access the right health and social care at the right time.

How do I participate and what are the consequences?

Participation in the interview is voluntary and your decision will not affect your care in any way. The interview is likely to last for 30 minutes.

To confirm your interest to take part in an interview, please return the 'Informed Consent' in this study pack. You are free to withdraw at any time and without giving a reason. If you like more information or would like to withdraw, please contact Jolien Vos by email (jvos@lincoln.ac.uk) or telephone (01522 886934).

It is likely that you will not directly derive any benefit from taking part, but your views and your participation will provide details and information that will be helpful in further developing the processes and procedures around the health and social care system. There are no known risks in taking part, but we do emphasize that the study team is available to you to explore any concerns you might have related to or following your participation in this study (details are provided below).

What happens to the information I give?

All the information you provide will be confidential. Only the researcher (Jolien Vos) will have full access to the data. The data are stored securely and password protected. All identifiable information, if there is any, is removed from the dataset. This dataset is only accessible to the research team (see further). The information will be processed in accordance to the University of Lincoln's Research Ethics Policy (2011) and Research Data Management policy.

Who is involved in this study?

- Jolien Vos: Graduate Research Assistant and PhD student at the University of Lincoln. She will be conducting the interviews.
- Dr Karen Windle: Reader in Health and Social Care at the University of Lincoln. She supervises this project.
- Prof Niroshan Siriwardena: Director of the Community and Health Research Unit at the University of Lincoln. He supervises this project.
- Dr Conor Linehan: Lecturer in Social Computing at the University College Cork. He supervises this project, in particular the last stage of tool development.
- Dr Kathrin Gerling: Lecturer in Social Computer Science at the University of Lincoln. She supervises this project, in particular the last stage of tool development.

E) Study Patient Information Sheets and Informed Consents

Questionnaire Version 2.1

Dear,

Title of Study: **Investigation of the potential role of ICT to support navigation of older adults with multiple morbidities through the care system and prototyping a tool to aid patients in this process.**

We would like to invite you to take part in a research study looking at how to improve navigation through the care system for patients with more than one long term condition. In the first phase of this study, participants are invited to help us gain insight in the people involved in their care.

This study is an important part of a doctoral research project carried out at the University of Lincoln, UK. We are seeking participants who currently live in England, are 55 years of age or older and have at least two long term conditions. In the first phase of this study we are gathering information through a questionnaire.

Please read the information in this study pack and feel free to contact us if you would like anything clarified or have any additional questions. If you would still like to consent to take part in this study, please sign the consent form in this study pack. Following this, you are asked to complete the questionnaire. Both can be returned by the envelope provided in the study pack.

Thank you for considering taking part in this project. The results will help to determine how we can improve the process of navigating the care system for older adults with multiple conditions.

Yours faithfully,

Jolien Vos
Graduate Research Assistant
PhD Student
Community and Health Research Unit
School of Health and Social Care
University of Lincoln
jvos@lincoln.ac.uk
+44 1522 88693

Dr Karen Windle
Reader
Supervisor of this project

UNIVERSITY OF
LINCOLN

Paper participant information

Title of Study: **Investigation of the potential role of ICT to support navigation of older adults with multiple morbidities through the care system and prototyping a tool to aid patients in this process.**

Thank you for considering taking part in this study looking at *care networks of older adults with multiple chronic conditions*. In this study we seek to gain a picture of the care network that surrounds you. For example, you may receive help from a number of clinicians and professionals, GPs, nurses, home carers as well as your family and friends. We would like you to tell us who supports you to live life as well as you can.

This questionnaire is an important part of a doctoral research project carried out at the University of Lincoln, UK. The results will help to determine how we can improve the process of navigating the care system for older adults with multiple chronic conditions.

We are looking for participants who meet the following criteria:

- Being 55 years old or more
- Having at least two chronic conditions
- Currently living in England

You will be asked to respond to some questions about yourself and the people in your care network. There are no right or wrong answers and all the information is anonymised and confidential. Participation in the questionnaire is voluntary and your decision will not affect your legal rights. If you do decide to take part, you are still free to withdraw at any time and without giving a reason. Withdrawal can be obtained by contacting the researcher (Jolien Vos) by email (jvos@lincoln.ac.uk) or telephone (+44 1522 886934).

All the information provided is handled confidential. Only the research team (Jolien Vos, Dr Karen Windle, Prof Niroshan Siriwardena, Dr Conor Linehan and Dr Kathrin Gerling) has access to the data, which are stored securely and password protected. All identifiable information, if there is any, is removed from the dataset. The information will be processed in accordance to the University of Lincoln's Research Ethics Policy (2011) and Research Data Management policy.

Taking part in the study gives you the opportunity to contribute to the improvement of health and social care delivery. You will also get the chance to be further involved by means of an interview, if that is something you wish. It is possible that you do not derive any particular benefit from taking part, but thanks to your participation you will deliver information that is useful for the further development and improvement of our care system. There are no known risks in taking part, but we do emphasize that the study team is available to you to explore any concerns you might have related and following to participation in this study (details are provided below).

This study has received ethical approval from the NHS Research Ethics Committee (REC reference number 15/NI/0263 and the University of Lincoln's School of Health and Social care.

Completing the questionnaire is expected to not take longer than 30 minutes. If you would like to participate, please complete the questionnaire in this study pack and send it back by envelope provided. Once again, thank you for your consideration taking part in this study. If you have any questions or want more information on the study, please feel free to contact us:

Jolien Vos
Graduate Research Assistant
PhD Student
Community and Health Research Unit
School of Health and Social Care, University of Lincoln
jvos@lincoln.ac.uk
+44 1522 886934

Dr Karen Windle
Reader
Supervisor of this project

UNIVERSITY OF LINCOLN

PATIENT CONSENT FORM

Title of Study: **Investigation of the potential role of ICT to support navigation of older adults with multiple morbidities through the care system and prototyping a tool to aid patients in this process.**

REC ref: ***[to be added after approval given]***

Name of Researcher:
Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet Version 2.1 dated 05/01/2016 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. ☐
3. I understand that any information about me will be kept secure and have a unique code so I cannot be identified from it. I understand that my personal details will be kept confidential. ☐
4. I agree to take part in the above study. ☐
5. Some people who consent might also be asked to take part in an interview to help the research team explore their experiences of their care network in more detail. Please tick the box if you would be willing to consider being contacted regarding taking part in an interview. You are under no obligation to take part in the interview even if you agree to the rest of the study. If you tick this box, please provide us with your contact details: ☐
   .....
   .....
   .....
   .....
6. Some people like to receive the results of the study they took part in. Please tick the box if you like to receive the results of this study and provide us with your contact details: ☐
   .....
   .....
   .....
   .....

Name of Participant	Date	Signature

Name of Person taking consent	Date	Signature

Interview Version 2.1

UNIVERSITY OF LINCOLN

Participant Study Sheet

What is this study about?

This study is being carried out at the University of Lincoln, UK. Its purpose is to help us gain an understanding of the support you receive regarding your care and how you manage these different types of support.

Based on this understanding we would like you to help us find ways in which we can improve care support for older adults with a number of health problems. The study has four main phases:

- Phase 1: Looking at the literature
- Phase 2: Data collection through a questionnaire
- Phase 3: Data collection through interviews
- Phase 4: Bringing together the questionnaire and interview data and think about how we can support older adults with multiple chronic conditions.

Who can take part?

We would welcome you responding to the questionnaire (Phase 2) if you currently live in England, are 55 years or older and have at least two long-term health problems (e.g., diabetes and high blood pressure or, depression and asthma), although you may well have a higher number of conditions (e.g., anxiety, diabetes, high-blood pressure and glaucoma). For the interview stage (Phase 3), we are particularly looking for participants living in Lincolnshire.

If I complete the questionnaire, why should I take part in an interview?

The questionnaire gave us an initial picture of those people that support you in receiving your care (care network). An interview will allow you to tell us more about your experiences of what goes well or what might be improved. This will help us to understand more about the types of support and the organisations involved. Combining both the information from the questionnaire and interview can help us develop a tool that will support older people to know how to access the right health and social care at the time that is right for them.

How do I participate and what are the consequences?

Participation in the interview is voluntary and your decision will not affect your care in any way. The duration of the interview can vary, but is likely to last for approximately 30-45 minutes.

To confirm your interest to take part in an interview, please can you return the completed 'Informed Consent' form in this study pack? If you do decide to take part, you are still free to withdraw at any time and without giving a reason. You can withdraw by contacting the researcher (Jolien Vos) by email (jvos@lincoln.ac.uk) or telephone (01522 886934). If you decide not to take part in an interview, this will not affect your care and you do not have to undertake further steps.

It is likely that you will not directly derive any benefit from taking part, but your views and your participation will provide details and information that will be helpful in understanding the health and social care system better. There are no known risks in taking part, but we do emphasize that the researcher can answer any question you may have following your participation in this study (details are provided below).

What happens to the information I give?

All the information provided is handled confidentially. The data are stored securely and will be password protected, so that only the researcher has access to it. All identifiable information, if there is any, will be removed from the dataset. The information will be processed in accordance to the University of Lincoln's Research Ethics Policy (2011) and Research Data Management policy.

It should be noted that there are limited instances when the study team are required to disclose data from the interviews. For example, if a participant reports inappropriate practice or intent to harm self or others, the study team will be required to report this to the appropriate authority (e.g. manager at the particular charity).

This study received ethical approval from the NHS Research Ethics Committee (REC reference number 15/NI/0263 and the University of Lincoln's School of Health and Social care.

Thank you for considering taking part in this project. If you have any questions, want more information on the study or like to receive a summary of the results from this study, please feel free to contact us:

Jolien Vos
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PhD Student
Community and Health Research Unit
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jvos@lincoln.ac.uk
01522 886934

Dr Karen Windle
Reader and Supervisor of this project
Community and Health Research Unit
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University of Lincoln
kwindle@lincoln.ac.uk
01522 886173

UNIVERSITY OF LINCOLN

PATIENT CONSENT FORM

Title of Study: **Investigating the feasibility and acceptability regarding the use of ICT to support older people with multimorbidity in their navigation through the care system.**

Name of Researcher:
Name of Participant:

Please initial box

1. I confirm that I have read and understand the information in this study pack for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my care or legal rights being affected. ☐
3. I understand that any information about me will be kept secure and have a unique code so I cannot be identified from it. I understand that my personal details will be kept confidential. ☐
4. I agree to take part in the above study by means of an interview and be recorded. ☐
5. I would like to receive a summary of the results of this study. If you tick this box, please provide us with your contact details: ☐

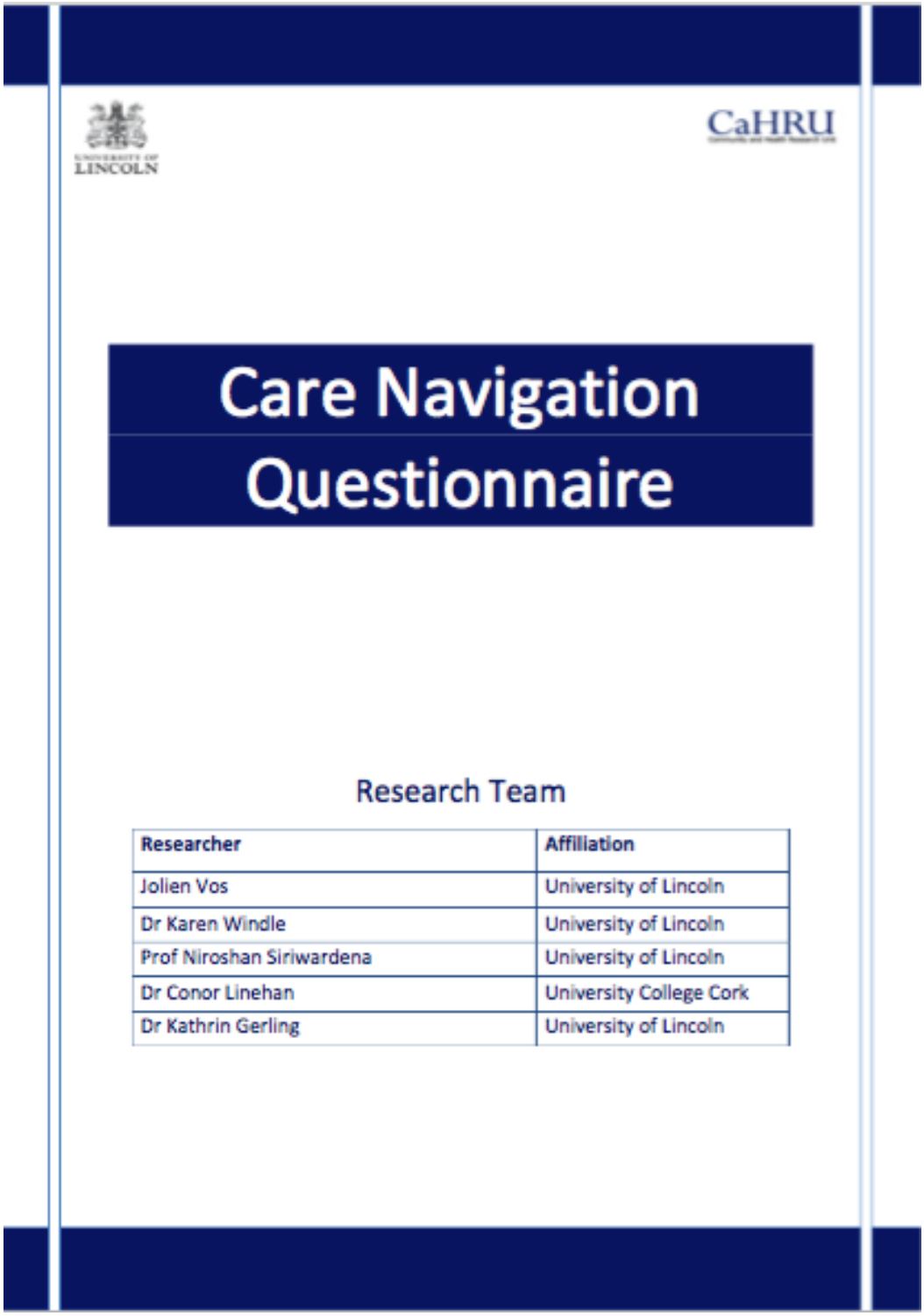
_____
_____
_____
_____

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant and 1 for the project notes

F) Study Questionnaire



Care Navigation Questionnaire

Research Team

Researcher	Affiliation
Jolien Vos	University of Lincoln
Dr Karen Windle	University of Lincoln
Prof Niroshan Siriwardena	University of Lincoln
Dr Conor Linehan	University College Cork
Dr Kathrin Gerling	University of Lincoln

Introduction

Dear participant,

Thank you for considering taking part in this study exploring ways to help older adults with multiple long term health conditions navigate the health and social care system. In this study we want to build a picture of your care network. We would like to hear your views about the different people involved in your care that are important to you or support you.

We are looking for participants who are:

- Aged 55 years or older
- Have at least two long term health conditions (e.g. diabetes and chronic lung disease)
- Living in England

We very much appreciate your support in this process. Attached you can find more details about the study.

If you have any questions, please contact Jolien Vos, researcher or Dr Karen Windle, project supervisor. Both are located in the School of Health and Social Care, Bridge House, University of Lincoln, Brayford Campus, Lincoln, LN6 7TS.
E-mail: jvos@lincoln.ac.uk/kwindle@lincoln.ac.uk. Telephone: 01522 886934

Once again, thank you for your consideration of taking part in this study.

Yours Sincerely,

Jolien

How to complete the questionnaire

You will be asked to respond to some questions about yourself and the people in your care network. There are no right or wrong answers and all the information will be anonymised and confidential.

Please answer the questions by:

- Ticking the box, like this ✓
- Or writing in the text box, like this I enjoy gardening

Completing the questionnaire is expected to take no longer than 20 minutes. Although the questionnaire involves several pages, it is likely that you can skip a lot of the sub questions.

After completion you can use the prepaid envelope in this study pack to send the questionnaire back to us.

About yourself

In this section you will be asked to answer questions that help us to gain an insight into which people are important to you in supporting you to live life as well as you can. There are no right or wrong answers.

1. a) What is your date of birth (DD/MM/YYYY):

   __ / __ / ____

   b) What is your sex?

   - ☐ Male
   - ☐ Female
   - ☐ Prefer not to say
   - ☐ Other: _____

Please take a moment to think about all the different people you interact with *(friends /family / formal and informal carers)*

2. Which people are **important** to you for your **'social'** care? (Multiple answers are possible and allowed, please select all those who are relevant to your social care. Health care providers are discussed in the next section.)

   - ☐ Community occupational therapist
   - ☐ Family support worker
   - ☐ Home care worker
   - ☐ Social work assistant
   - ☐ Social worker
   - ☐ None of the above
   - ☐ I don't know
   - ☐ Other or social organisations (please specify)

3. For each of the below, please indicate the frequency, type and reason for contact with these people as well as the type of support they give you and how well this answers your needs.

a) Community occupational therapist

☐ I don't have any contact with this professional → Go to question 3.b)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different occupational therapists have you seen in the last 6 months?

4

b) Family support worker

☐ I don't have any contact with this professional → Go to question 3.c)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different family support workers have you seen in the last 6 months?

5

c) **Home care worker**

☐ I don't have any contact with this professional → Go to question 3.d)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different home care workers have you seen in the last 6 months?

d) Social work assistant

☐ I don't have any contact with this professional → Go to question 3.e)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different social work assistants have you seen in the last 6 months?

e) Social worker

☐ I don't have any contact with this professional → Go to question 3.f)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different social workers have you seen in the last 6 months?

f) Other or organisations (please specify:_____)

☐ N/A → Go to the next question

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different other social organisations have you seen in the last 6 months?

4. On average, how many different professionals did you see with regard to your 'social' care in the last 6 months?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ More than

5. Which people, based in the community (i.e. outside the hospital), are **important** to you for your '**health**' care? (Multiple answers are possible and allowed, please select all those who are relevant to you. Professionals based in the hospital are included in the next section)

- ☐ Clinical psychologist
- ☐ Clinical support worker nursing
- ☐ Community chiropodist/podiatrist
- ☐ Community nurse (district nurse)/ nurse specialist
- ☐ (Community) pharmacist
- ☐ Community physiotherapist
- ☐ Community speech and language therapist
- ☐ Dentist
- ☐ General practitioner (GP)
- ☐ Health visitor
- ☐ NHS community occupational therapist
- ☐ Nurse (GP practice)
- ☐ Nurse (mental health)
- ☐ None of the above
- ☐ I don't know
- ☐ Others or organisations (please specify)

6. For each of the below, please indicate the frequency, type and reason for contact with these people as well as the type of support they give you and how well this answers your needs.

a) Clinical psychologist

☐ I don't have any contact with this professional → Go to question 6.b)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different clinical psychologists have you seen in the last 6 months?

b) Clinical support worker nursing

☐ I don't have any contact with this professional → Go to question 6.c)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different clinical support workers nursing have you seen in the last 6 months?

c) Community chiropodist/podiatrist

☐ I don't have any contact with this professional → Go to question 6.d)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different community chiropodists/podiatrists have you seen in the last 6 months?

d) Community nurse (district nurse)/ specialist nurse

☐ I don't have any contact with this professional → Go to question 6.e)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different community nurses/ specialist nurses have you seen in the last 6 months?

e) (Community) pharmacist

☐ I don't have any contact with this professional → Go to question 6.f)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different (community) pharmacists have you seen in the last 6 months?

f) Community physiotherapist

☐ I don't have any contact with this professional → Go to question 6.g)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different community physiotherapists have you seen in the last 6 months?

g) Community speech and language therapist

☐ I don't have any contact with this professional → Go to question 6.h)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different community speech and language therapists have you seen in the last 6 months?

h) Dentist

☐ I don't have any contact with this professional → Go to question 6.i)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different dentists have you seen in the last 6 months?

i) General practitioner (GP)

☐ I don't have any contact with this professional → Go to question 6.j)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different GP's have you seen in the last 6 months?

j) Health visitor

☐ I don't have any contact with this professional → Go to question 6.k)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different health visitors have you seen in the last 6 months?

k) Community occupational therapist

☐ I don't have any contact with this professional → Go to question 6.l)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different community occupational therapists have you seen in the last 6 months?

l) Nurse (GP practice)

☐ I don't have any contact with this professional → Go to question 6.m)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different nurses (GP practice) have you seen in the last 6 months?

m) Nurse (mental health)

☐ I don't have any contact with this professional → Go to question 6.n)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different mental health nurses have you seen in the last 6 months?

n) **Others or organisations (please specify:_____)**

☐ I don't have any contact with this professional → Go to the next question

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different organisations have you seen in the last 6 months?

7. On average, how many different professionals based in the community did you see with regard to your 'health' care in the last 6 months?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ More than 10

8. Which people, based in the hospital, are **important** to you for your **'health'** care? (Multiple answers are possible and allowed, please select all those who are relevant to you.)

- ☐ Allied health professional support worker
- ☐ (Associate) specialist
- ☐ Clinical support worker
- ☐ Hospital dietitian
- ☐ Hospital nurse
- ☐ Hospital occupational therapist
- ☐ Hospital pharmacist
- ☐ Hospital physiotherapist
- ☐ Hospital radiographer
- ☐ Hospital speech and language therapist
- ☐ Medical consultant
- ☐ Psychiatric consultant
- ☐ Surgical consultant
- ☐ Other hospital doctors
- ☐ None of the above
- ☐ I don't know
- ☐ Others or organisations (please specify)

9. For each of the below, please indicate the frequency, type and reason for contact with these people as well as the type of support they give you and how well this answers your needs.

a) Allied health professional support worker

☐ I don't have any contact with this professional → Go to question 9.b)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different allied health professional support workers have you seen in the last 6 months?

b) (Associate) specialist

☐ I don't have any contact with this professional → Go to question 9.c)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different specialists have you seen in the last 6 months?

c) Clinical support worker

☐ I don't have any contact with this professional → Go to question 9.d)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different clinical support workers have you seen in the last 6 months?

d) Hospital dietitian

☐ I don't have any contact with this professional → Go to question 9.e)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different hospital dietitians have you seen in the last 6 months?

e) Hospital nurse

☐ I don't have any contact with this professional → Go to question 9.f)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different hospital nurses have you seen in the last 6 months?

f) Hospital occupational therapist

☐ I don't have any contact with this professional → Go to question 9.g)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different hospital occupational therapists have you seen in the last 6 months?

g) **Hospital pharmacist**

☐ I don't have any contact with this professional → Go to question 9.h)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different hospital pharmacists have you seen in the last 6 months?

h) **Hospital physiotherapist**

☐ I don't have any contact with this professional → Go to question 9.i)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different hospital pysiotherapists have you seen in the last 6 months?

l) Hospital radiographer

☐ I don't have any contact with this professional → Go to question 9.j)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different hospital radiographers have you seen in the last 6 months?

j) Hospital speech and language therapist

☐ I don't have any contact with this professional → Go to question 9.k)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different hospital speech and language therapists have you seen in the last 6 months?

k) Medical consultant

☐ I don't have any contact with this professional → Go to question 9.l)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different medical consultants have you seen in the last 6 months?

l) Psychiatric consultant

☐ I don't have any contact with this professional → Go to question 9.m)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different psychiatric consultants have you seen in the last 6 months?

m) Surgical consultant

☐ I don't have any contact with this professional → Go to question 9.n)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different surgical consultants have you seen in the last 6 months?

n) Other hospital doctors

☐ I don't have any contact with this professional → Go to question 9.o)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different hospital doctors have you seen in the last 6 months?

o) **Others or organisations (please specify:_____)**

☐ I don't have any contact with this professional → Go to the next question

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Reason for contact

- ☐ Short term problem not related to my chronic condition(s)
- ☐ Short term problem related to my chronic condition(s)
- ☐ Chronic condition

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

Roughly how many different organisations have you seen in the last 6 months?

10. On average, how many different professionals based in the hospital did you see with regard to your 'health' care in the last 6 months?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ More than 10

11. Which people in your daily life do you perceive as being **important** in you care? (Multiple answers are possible and allowed, please select all those who are relevant for you.)

- ☐ Children
- ☐ Family/relatives
- ☐ Friend(s)
- ☐ Neighbour(s)
- ☐ Partner/spouse
- ☐ None of the above
- ☐ Others or organisations (please specify)

12. For each of the below, please indicate the frequency, type and reason for contact with these people as well as the type of support they give you and how well this answers your needs. (Note: we are talking about support regarding your health and social care.)

a) Children

☐ I don't have any contact → Go to question 12.b)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

b) Family/relatives

☐ I don't have any contact → Go to question 12.c)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

c) Friend(s)

☐ I don't have any contact → Go to question 12.d)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

d) Neighbour(s)

☐ I don't have any contact → Go to question 12.e)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

e) Partner/spouse

☐ I don't have any contact → Go to question 12.f)

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

f) **Others or organisations (please specify:_____)**

☐ I don't have any contact → Go to the next question

Frequency of contact

- ☐ Every day
- ☐ Once or more a week, but not every day
- ☐ More than once a month, but not every week
- ☐ Once a month
- ☐ Every 1 or 2 months
- ☐ Every 3 or 4 months
- ☐ Every 5 or 6 months
- ☐ Every 7 to 12 months
- ☐ I don't know

Main way of contact

- ☐ Electronically (e.g., email)
- ☐ By telephone
- ☐ In person (face to face)

Main type of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Other types of support provided

- ☐ Information and advice
- ☐ Emotional support
- ☐ Practical support
- ☐ Care (e.g., assessment, treatment, prescription)

Level of satisfaction with support

- ☐ Very unsatisfied
- ☐ Unsatisfied
- ☐ Satisfied
- ☐ Very satisfied

13. How do you feel about navigating (i.e. finding the right service at the right time) the care system?

- ☐ I find it extremely difficult.
- ☐ I find it difficult.
- ☐ I find it somewhat difficult.
- ☐ I find it somewhat easy.
- ☐ I find it easy.
- ☐ I find it extremely easy.

14. What is the main reason(s) you feel this way?

Background information

In this section you will be asked about yourself and any of the long term health conditions you may have. There are no right or wrong answers.

1. Which of the following long term health conditions have you been diagnosed with? (Multiple answers are possible and allowed, please select all the options that apply to you.)

- ☐ Prefer not to answer
- ☐ Cancer
- ☐ Cardiovascular disease (e.g., heart disease, stroke, high blood pressure)
- ☐ Chronic back pain
- ☐ Chronic bowel disease (e.g., irritable bowel syndrome, Chrohn's disease)
- ☐ Chronic fatigue syndrome
- ☐ Chronic kidney disease (e.g., kidney failure)
- ☐ Chronic neurologic disorder (e.g., Alzheimer, dementia, epilepsy, muscular disease)
- ☐ Chronic respiratory disease (e.g., asthma, chronic obstructive pulmonary disease [COPD])
- ☐ Chronic skin disease (e.g., psoriasis)
- ☐ Diabetes
- ☐ HIV/AIDS
- ☐ Liver disease (e.g., liver cirrhosis)
- ☐ Mental illness (e.g., schizophrenia, bipolar disorder, depression)
- ☐ Musculoskeletal disease (e.g., arthritis, rheumatism, osteoporosis)
- ☐ Thyroid problems
- ☐ Other (please specify:_____)

2. How many long term health conditions are you currently diagnosed with? (please write down the total number of long term health conditions)

3. How long ago were you diagnosed with your 'first' long term health condition?

- ☐ Less than 6 months
- ☐ More than 6 months, but less than 1 year
- ☐ 1 year or more, but less than 2 years
- ☐ 2 years or more, but less than 5 years
- ☐ 5 years or more, but less than 10 years
- ☐ 10 years or more
- ☐ I don't know
- ☐ Other (please specify:_____)

4. How long since your most recent long term health condition was diagnosed?

- ☐ Less than 6 months
- ☐ More than 6 months, but less than 1 year
- ☐ 1 year or more, but less than 2 years
- ☐ 2 years or more, but less than 5 years
- ☐ 5 years or more, but less than 10 years
- ☐ 10 years or more
- ☐ I don't know
- ☐ Other (please specify:_____)

5. Which ethnic group describes your background the best? (please select one group and specify the subgroup).

- ☐ White
  - ☐ English/Welsh/Scottish/Northern Irish/British
  - ☐ Irish
  - ☐ Gypsy or Irish Traveller
  - ☐ White European (e.g., Polish, French)
  - ☐ Other white background (e.g., Australian) – please specify:_____

- ☐ Mixed/Multiple ethnic groups
  - ☐ White and Black Caribbean
  - ☐ White and Black African
  - ☐ White and Asian
  - ☐ Any other mixed/multiple ethnic background – please specify:_____

- ☐ Asian/Asian British
  - ☐ Indian
  - ☐ Pakistani
  - ☐ Bangladeshi
  - ☐ Chinese
  - ☐ Any other Asian background – please specify:_____
- ☐ Black/African/Caribbean/Black British
  - ☐ African
  - ☐ Caribbean
  - ☐ Any other Black/African/Caribbean/Black British group – please specify
- ☐ Other ethnic group
  - ☐ Arab
  - ☐ Any other group – please specify:_____

6. Where do you currently live in England?

- ☐ Prefer not to answer → *Go to question 10*
- ☐ East Midlands → *Go to question 7*
- ☐ East of England → *Go to question 10*
- ☐ London → *Go to question 10*
- ☐ North East England → *Go to question 10*
- ☐ North West England → *Go to question 10*
- ☐ South East → *Go to question 10*
- ☐ South West → *Go to question 10*
- ☐ West Midlands → *Go to question 10*
- ☐ Yorkshire & Humber → *Go to question 10*
- ☐ Other (please specify:_____)

7. Which region within East Midlands do you currently live in?

- ☐ Prefer not to answer
- ☐ Nottinghamshire
- ☐ Derbyshire
- ☐ Leicestershire
- ☐ Rutland
- ☐ Northamptonshire
- ☐ Lincolnshire

8. Would you like to participate in an interview, about the role different people play with regard to your care, for this study? (Please do not forget to provide us with your contact details below)

☐ Yes ☐ No

9. Are you currently living in or within a 10 mile radius of Lincoln City?

☐ Yes ☐ No

10. Would you like to be contacted by a researcher to talk a little about whether you found this questionnaire difficult or if anything concerns you regarding this questionnaire?

☐ Yes ☐ No

11. How would you like to be contacted? (Please fill out the details for the method of contact you prefer.)

Name:

Address

City/Town

County

Postal Code

Country

Email address

Phone number

You have reached the end of this questionnaire. If you have any other comments about please express them below (this could include comments from the interviewee or problems completing the questionnaire)

Contact details:

Jolien Vos
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PhD Student
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01522 886934

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Community and Health Research Unit
School of Health and Social Care
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Brayford Pool
Lincoln, LN6 7TS

Thank you for taking the time to complete this questionnaire

CaHRU

Appendix 5: Interview Topic Guide (October 2015)

Introduction

The purpose of this interview is to explore your experience on the care network that surrounds you. We are trying to gain an insight into how the care network surrounding older adults with multimorbidity functions.

There are no right or wrong answers; the interview is simply about hearing your views on this topic and learning from your experience.

There might be moments during the interview at which we take a look at some of your data from the questionnaire. This can help us build the image of your care network and work with concrete examples.

We will not use your name in any reports of this work and it will not be made known who took part. However, some of the things you say in the interviews might be used to illustrate and support the findings of the research. We will make every effort to make sure that these remain unidentifiable.

Are you happy for this interview to be tape recorded? Only researchers who are part of the team will have access to the recording and you will not be named on the tape.

1 THE CARE NETWORK	
Question	Prompts
1.1 Could you first tell me what you understand by the term 'care network'?	• What does this mean to you? • Who supports you regarding your care? • Who is involved in your (social and health) care? • Who is important to you in your (social and health) care?

1.2 How has having a number of health problems or different diagnoses shaped this care network?	• To what extent did it increase the amount of people involved in your care? • To what extent did it complicate your life?
2 ROLES AND RESPONSIBILITIES	
2.1 Could you tell me something about how and what you do to stay healthy?	• What do you do to remain your well-being? • How do you manage your different health conditions?
2.2 What do you feel is the role of the people involved in your 'care'?	• E.g., where do you feel your 'role' as a 'patient' stops and the role of the others start? • What is the role of friends, relatives, neighbours, etc.? • What is the role of social care providers? What is the role of health care professionals?
3 RELATIONSHIPS AND INTERACTION	
3.1 How do you feel about these roles?	• To what extent would you like more/less responsibility? • To what extent do you think this is in balance? • To what extent do you feel 'in control' of/listened to for your own care?
3.2 Tell me something more about how the people that support you, interact with you?	• How do they communicate with you? • If so, how? If not, what do you think about this?
3.3 Tell me something more about how they work with/or alongside each other?	• Do people know about the other people involved in your care? • Do they communicate with each other? • If so, how? If not, what do you think about this?
3.4 What things do you think work well across your care network?	• Who/What are you satisfied with and why? • Who/What are you less satisfied with and why?

3.5 What could be improved across your care network?	• For instance, what is the communication like between your GP and specialists you see in the hospital? • How could this be improved for you?
4 NAVIGATING THE CARE SYSTEM/NETWORK	
4.1 How do you manage your care network practically when having a number of health problems or diagnoses?	• For instance, some people see many care providers and have a busy schedule of appointments, how is this for you? • How do you know who to contact, go to, with which concern?
4.2 What makes you finding your way through the health and social care support that you need, easier?	• Which information do you rely on to know who to go to? • Who informs you about the services available to you? • Which people do you rely on to know who to go to?
4.3 What makes finding your way through the health and social care support that you need, difficult?	• For instance, some people find it difficult to juggle the different sites at which they need to be to get the help they need. How is this for you? • What could be improved? • What would be helpful for you to find your way through the system?
5 TECHNOLOGY AND HOW IT COULD SUPPORT	
5.1 Can you tell me something about technology (e.g., mobile phone, computer) you currently use?	• For what do you generally use these? • If they don't use: What do you think about technology? • How do you use it in relation to health and social care (e.g., booking appointments)?
5.2 In an ideal world, what would the care system look like for you?	• How would it function ideally? • What things are in place in this world to help you?
6 ROUND-UP	

Thank you very much for your time and your help with this study! Are there any further comments you would like to make that you don't think we picked up through the discussion?
FIELD NOTES/OBSERVATIONS

Appendix 6: Data Extraction Chart for Scoping Review

ITEM IN FRAMEWORK	DESCRIPTION
TITLE	Full title of the study or report as it occurs in the publication.
TYPE LITERATURE	Describe the selected paper as accurate as possible by selecting one of the following options: 1 Research 2 Project description 3 Case study or case report 4 Conference abstract 5 Conference paper
YEAR	The year of publication of the report or paper.
AUTHORS	Names of authors of report or paper.
STUDY LOCATION	Description of the country and if applicable specific region where the study took place.
STUDY AIM	Aims and purposes of the study or report.
DESIGN/METHODOLOGY	If the selected paper involved a research study, description of the design and methodology used (i.e. qualitative, quantitative or mixed method research).
SAMPLE CHARACTERISTICS	If the selected paper was labelled as 'research', description of sample characteristics (e.g. age, sample size).
IMPORTANT RESULTS	Summary of important results and significant findings in relation to the research question of the scoping review.
JOURNAL/PUBLICATION	Full details of the journal in which the study was published or the organisation that provided the report.
RELEVANCE NOTES	Notes on the relevance of the selected paper in relation to the research question of the scoping review (use of PICO as guidance).

Appendix 7: Framework for (qualitative) analysis with study example quotes

INTERVIEW CODE	THEMES			
	Theme 1: Meaning of the Personal Care Network			
	1.1 PCN description	1.2 Formal and informal care	1.3 NHS and private care	1.4 Primary, secondary and tertiary care
[INSERT PARTICIPANT CODE]	To me it means sort of everybody that you're connected with… euhm family, friends, people I've met and have become friends with since I moved down here, which has been important to me (#3)	I: Mhm, euhm does it include others, such as your partner, family… PP: No, I wouldn't think so no, I think it's just the system (#2)	I: Mhm, euhm does it include others, such as your partner, family… PP: No, I wouldn't think so no, I think it's just the system (#2)	… from GP to euhm primary care, secondary care and so on (#2)
	Theme 2: Structure of the Personal Care Network			
	2.1 Shape of the PCN	2.2 Composition	2.3 Changes in the PCN	

[INSERT PARTICIPANT CODE]	See participants' pre and post PCN graph		Oh my neighbours are important to me definitely, and my friends again yes (#1).		Well it has changed because I am having to caricatures it a bit because I hardly ever used to go and see my G.P. for anything. You know I went to see my G.P. for instance because I went to have a vasectomy and that was a long time ago. But in between those highly exceptional I rarely saw my G.P. But then I think over the last year or nine months I have been seeing my G.P. on a much more regular basis (#5).		
	Theme 3: Roles and responsibilities in the PCN						
	3.1 Patient	3.2 Community	3.3 Family	3.4 Friends	3.5 Primary Care	3.6 Expert care/hospital	3.7 Additional organisations and third sector care
[INSERT PARTICIPANT CODE]	RES: Yeah, well, my responsibility is obviously to keep as healthy as possible, mentally and physically… euhm some	And this to me is that sort of care in the community is where people look out for each other you know? [...]	My partner yes […] Emotional, practical as well because there are things that I can't do. That's really why I took him you	Euhm, I occasionally but not all that regularly, sometimes use a friend of church for attending the doctor at	So I asked my G.P. for a referral to orthopaedics. And I was first referred to one of the orthopaedic consultants and because I had previously had another in that my	So I have to go to haematology to have my blood checked. And I have had to have bits which would remain stable	Right, what they are (ileostomy association); They do home visits to start off with and then they do a monthly meeting in a pub, once a month at ((Pub Name)).every three

	people question my mental euhm (joint chuckling) well-being I think at times at least my children do.. euhm that euhm I think that's a main responsibility. Another one is obviously euhm attend to anything with the doctor or nurse or medical health dentist etc. before it becomes a critical issue sooner rather than later in	Even a casual greeting of, "are you alright today?" You know it means that they're asking you if you are alright and is there anything that you need... or can I help in any way you know? It's, so that's nice but it is basically I think; well that is what I think of the care system [...] I think you think of hospitals	know (laughs)… (#2).	surgery when I haven't been able to drive myself (#6).	right hip had been operated on. I asked to be referred to the consultant who had done my right hip (#5).	over some time so I haven't had to have to have any blood transfusions (#1).	to four months we go out for a bigger meal, and then they do a couple of events with the hospital and they hold a few coffee morning as well as everything else (#7).

	other words (#6).	and doctors and nurses and things as services when you need them (#1).	
	Theme 4: First point of contact		
	4.1 PCN		4.2 Wider care system
[INSERT PARTICIPANT CODE]	But otherwise no, with the chest and everything I just have go to the doctor and she says oh yes you better go to the hospital (#1).		INT: Okay so your G.P. is sort of your first point of contact when you feel something isn't quite right. RES: Absolutely. But I have also got you know stoma care team so if; if right with the stoma care team because it is me what I do is every time they want, yeah a bit like yourself; every time they want any help either trailing new products or whatever that sort of thing, they contact me and the reason why I don't mind them contacting me is that they all know me by first name now. As soon as I phone up, so any extra help or support I ever need you know, because it's great yeah, lots of people might see they've had the operation and they might never see them again in your life and as soon as there are any new bags, or new trials, new products, new anything that sort of thing. The first person they contact is me and because of that sort of thing it means that most of the time when I have got any extra questions or

			anything about anything on short notice I can contact them people. So if I was struggling with soreness or you know bag not sticky enough or anything sort of thing I can contact these people sort of straight away, so they are a very, very useful source of information (#7).	
	Theme 5: Service Organisation – Operation			
	5.1 Internal (continuity)	5.2. External (referral)	5.3 The PCN	5.4. The wider system
[INSERT PARTICIPANT CODE]	I: OK, so when you go for follow-up, is it always the same person or how does it work? PP: No, it's the NHS my dear (laughs) (#2).	I: Through the GP, and then euhm, are the always the same person? PP: No, you've to go to the hospital, I mean, sometimes I've been to Lincoln hospital and sometimes to Gainsborough. So, yeah, haven't been seeing the same people (#2).	Again, that was, you used to, the GP would give you euhm euhm contact the let's say the crisis team but now all the GP does is give you a phone number or an email address and then you you email. It's all good when you're well, but when you're not well, you don't want to be emailing and then you've got to wait 18 weeks for someone from the mental health team to contact you. You know, you fill in a, they send you a form and they're based in Sleaford or	Well they say they would ring you on a certain day or that they'd come and see you on a certain day and didn't communicate with somebody else so therefore… they didn't, they had they'd forgotten to make an appointment or they hadn't written it in their diary at that particular moment whereas I'm quite practical, I write things down in my diary then I know that somebody is coming to see me. Like, say for example, like I knew

			Grantham or something like that, which is 20 odd miles away and when… when you're, when I had that meltdown euhm the GP came to me "Oh but you was all right yesterday", I know I was all right yesterday but it just happened. Euhm, but you was all right yesterday so you don't need any input, you get on with it (#4).	you was coming this morning at half past ten, so I made sure I was up and washed and showered and dressed and my hair done and what have you, euhm… Whereas I'm still waiting for someone input into my care and they told me there would be a few weeks wait… I think I'm on my third month now that I'm still waiting for that call, euhm for them to come and reassess me. Euhm, because I had care euhm and then suddenly I get a phone call, a letter to say oh you got x amount of pounds a week for your care (#4).
	Theme 6: PCN Interaction and Communication			
	6.1 Patient-provider	6.2 Provider-provider	6.3 Services	

[INSERT PARTICIPANT CODE]	INT: And how is that? How would you like to be treated? RES: Always with respect always with a little bit of a smile on their face and always reasonably sort of gentle because a lots of the time even with what I've got they'll say right on the bed and get on your knees. And you need help sometimes getting your clothes on and off so always to at least be asked that. Then you know; sorry and then they'll press so hard and its, it makes feel as if do you know what I mean (#7).	PP: That's right, no communication, one can't, one screen won't talk to the… I thought with all thing like computers and what have you and all the information they've got on you, because they know everything about you, like big brother, they know everything, even know what colour socks I'm wearing and things like that… euhm, but they can't communicate, no communication between one department and another… I: Mhm PP: You know, it's ridiculous! They should have one whole data, I know it would be a huge database, but they would be able to… you know all this business with that they said they gonna let, you can access your medical record? (#4)	PP: Yes, there is a lot of different services. I: Mhm, so, how should we get them communicating with one another? PP: There again, it's the people working in it isn't it. I suppose that if there were any problems, he would communicate it, the option is there but I don't see any need for him to sort of go and do together (#3).
	Theme 7: Technology		
	7.1 Technology for/in care		7.2 Personal use of technology

[INSERT PARTICIPANT CODE]	I'm on a forum for diabetes, I know lots of people on there euhm I look up, all the while I'm looking at things you know, questions and answering, yeah it's a wonderful piece of technology. I got my computer, my laptop but very rarely use it, I got my phone and tablet (Jackie).	Well, I got a kindle, just a kindle with books on, I got a kindle fire HD which you can do everything on, I got the internet on, you know so, I can go in, I can found out what's on the internet, I can find out what's happening in the world, there's games on of course, there's a clock, there's a computer, there's euhm an alarm clock, I set that when I'm away or if I need it. What else is on? Just everything with this kindle, it's like a computer, it's like a laptop, so you got your Facebook, you got your emails, you name it, you can get it on. But I also got a laptop which I use a lot as well. If I want to write something, like I tried to write you yesterday, on the Kindle and it kept flipping off. If you've got your finger to near anything and I, I didn't even know whether it got there or not and then I got your reply and I know well it did, you got one of them (laughs) (Joan).